CHSD
Centre for Health Service Development

Caring Communities: evaluation of a national palliative care program

CaringCommunities:evaluationofanationalpalliativecareprogramCaringCommunities:evaluationofanationalpalliativecareprogramCaringCommunities:evaluationofanationalpalliativecareprogramC

Karen Quinsey

Kathryn Williams

Dave Fildes

Malcolm Masso

Kate Senior

Heather Yeatman

Kathy Eagar

Suggested citation

Quinsey K, Williams K, Fildes D, Masso M, Senior K, Yeatman H and Eagar K (2006) ***Caring Communities: evaluation of a national palliative care program***. Centre for Health Service Development, University of Wollongong.

Table of Contents

1 MAIN MESSAGES 1

2 INTRODUCTION 3

2.1 Background 3

2.2 Method of the national evaluation 4

2.2.1 Evaluation framework 4

2.2.2 Methodology 5

3 THE IMPACT AND OUTCOMES OF THE CARING COMMUNITIES PROGRAM 8

3.1 Level 1: Impacts on, and outcomes for, consumers 8

3.2 Level 2: Impacts on, and outcomes for, providers 10

3.2.1 Volunteers 10

3.2.2 Primary care and allied health professionals 11

3.2.3 Specialist palliative care professionals 14

3.3 Level 3: Impacts on, and outcomes for, the care delivery system 14

3.3.1 Knowledge and skills of carers and communities 14

3.3.2 Community awareness and understanding of palliative care 15

3.3.3 Care coordination for people who are dying and their families 17

3.3.4 Accessible and integrated care through strong provider partnerships 18

3.4 Sustainability, Capacity Building and Generalisability 20

3.4.1 Sustainability 21

3.5 Capacity Building 24

3.6 Generalisability 27

3.6.1 Discussion: Sustainability, Capacity Building and Generalisability 30

3.7 Dissemination 30

4 THE STRATEGIES AND PROCESSES OF THE CARING COMMUNITIES PROGRAM 32

4.1 Program-level strategies and processes 32

4.1.1 Program planning and project selection 32

4.1.2 Governance and Expert Advice 33

4.1.3 Program Management by the Department 34

4.1.4 Review of project plans and evaluability assessment 38

4.1.5 Evaluation tool kit 39

4.1.6 Communication and support strategies 42

4.1.7 Ethics 47

4.1.8 Role of Palliative Care Australia 48

4.1.9 Role of Australian Government DoHA officers 48

4.1.10 Role of State and Territory government officers 50

4.1.11 Role of the National Evaluation Team 51

4.1.12 Reporting requirements 52
4.2 Project-level strategies and processes 54
4.2.1 Project goals and objectives 54
4.2.2 Community needs addressed by the project 54
4.2.3 Engaging stakeholders 55
4.2.4 Project management: what worked? 57
4.2.5 Difficulties and barriers 58
4.2.6 Project evaluation 59
5 DISCUSSION AND CONCLUSIONS 62
5.1 Impact of CCP 62
5.2 Program management 63
5.3 Project management 63
5.4 Sustainability 64
APPENDIX 1 – THE CCP PROJECTS INDEXED BY THEME 65

List of Tables

Table 1 Response rates for checklist tools at three time points 21
Table 2 Responses to Sustainability Tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points) 22
Table 3 Responses to Capacity Building tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points) 24
Table 4 Responses to Generalisabiity Tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points) 28
Table 5 Evaluability Assessment Summary 39
Table 6 Use of tools from the CCP evaluation tool kit 40
Table 7 Site Visits made 2003-2005 46
Table 8 Numbered list of Caring Communities Program projects 65
Table 9 CCP projects indexed by theme 66

List of Figures

Figure 1 Total number of monthly ‘hits’ to the CCP and Palliative Care web pages 44
Figure 2 Monthly downloads of the evaluation bulletins 44

1 Main messages

- The CCP funded a wide variety of projects, which had some advantages and some disadvantages. There is some evidence that improvements resulting from individual projects will be sustained. The true test will come in 6-12 months time and consideration should be given to conducting a review around that time period to ascertain what has been sustained and what has not.
- The major achievement for CCP was in the area of building relationships, networking and community engagement, all of which are time consuming and challenging. If anything will be sustained it will be the relationship building between providers.
- Many projects sought to raise community awareness. Although well meaning this presents a problem due to the difficulty in measuring whether this has been achieved or not. There is a need to be cautious in future about projects that aim to raise community awareness.
- Many projects focused on education of health professionals, resulting in a range of views about the best way to provide such education. Sustainability of education is very sensitive to the availability of ongoing funding.
- There is little evidence that the CCP had much impact on consumers (patients, carers, families) but this is not surprising given that the major focus of the program lay elsewhere. However, in part, this result was due to projects including little evaluation of consumer outcomes in their evaluation.
- Project level evaluation tended to use surveys (to assess knowledge or satisfaction) rather than measure changes in practice or behaviour.
- Projects in rural and remote and/or Aboriginal and Torres Strait Islander communities struggled to establish themselves and maintain progress. Many of the reasons for this are common to both types of projects but remoteness is the more problematic of the two.
- The CCP produced lots of written and audiovisual material (e.g. education programs) that is potentially very useful to others. To gain maximum advantage from this work consideration should be given to peer reviewing the material and actively disseminating it.
- The hub and spoke model of program management whereby the spokes of DHA state officers were supported by a central hub generally worked well but was open to interpretation and adversely impacted by staff turnover.
- Involvement of State health department officers was good early on in the program but declined as the CCP progressed.
- Development of a CCP Toolkit was a good idea but was delivered too late in the establishment of the CCP to be of much use to the majority of projects.
- Some CCP projects have successfully applied for further project funding. This is a positive development but does perpetuate reliance on project funding rather than incorporating changes into ‘day to day’ practice and resources.
- There was considerable variability in project management experience across projects. The employment of dedicated project staff tended to work better than having staff try and juggle their substantive position and a project position.
- In those instances where projects engaged their own (local) independent evaluators the separation of project management and evaluation tasks worked well and assisted knowledge transfer from evaluators to project staff.
- There was considerable variability in the level of support required by individual projects. The National Evaluation Team were not detached observers but were prepared to intervene when projects were at risk.

- Exception reporting for project progress reports seemed like a good idea to reduce workload but proved to hard to follow for those reading the reports.
- For future projects (not necessarily just those focused on palliative care) it would be worth developing a 'project orientation manual' containing standard templates for project plans, progress reports and final reports to establish clear expectations for project staff early on.
- The first national workshop for CCP was not as effective as it could have been but the second workshop was very successful. The second workshop provided a valuable opportunity to place project work within the context of the CCP and the national palliative care strategy and provided opportunities for networking and the sharing of lessons learnt.
- Site visits were a valuable part of the evaluation, giving the National Evaluation Team an opportunity to discuss project documentation with project staff, gain an understanding of project context and assess available skills and project risks.
- The capacity building, sustainability and generalisability tools proved to be useful, not only in informing the national evaluation but in stimulating thought and discussion on these issues at the project level.

2 Introduction

This document is one of three that make up the final report for the national evaluation of the Caring Communities Program (CCP), a national palliative care program funded by the Australian Government between April 2003 and May 2006. The other two sections of the report are

- *Caring Communities: report to the Australian Government on the national evaluation*, which describes the processes of the national evaluation; and
- *Caring Communities: a description of the 37 projects of a national palliative care program*, which contains a short description of each of the projects, along with an index.

2.1 Background

The National Palliative Care Strategy (NPCS) was endorsed by the Australian Health Ministers' Advisory Council (AHMAC) in October 2000 following consultation with a range of key stakeholders. This national approach to palliative care is a commitment of the Australian, State and Territory Governments, palliative care service providers and community based organisations to deliver palliative care policies, strategies and services in a consistent way across Australia.

The development of this strategy articulated the essential ongoing role of palliative care within health care and highlighted the importance of research to the development of palliative care. In support of this, the Australian Government has made available a total of $201.2million throughout the five years of the Australian Health Care Agreements (2003-2008) for palliative care. Of this, $188 million is broadly allocated on a per capita basis to States and Territories for continued service provision, and $13.2 million for the Australian Government to implement a national program of activities.

The above funding arrangements are further supported through the Australian Government's commitment in the 2002 Federal Budget of $55 million over four years (2002/03 - 2005/06) for national activities to improve the standard of palliative care offered local communities.

This $55 million Budget initiative, combined with the $13.2 million allocated under the Australian Health Care Agreement for national activities is known as the National Palliative Care Program.

The goal of the National Palliative Care Program is to improve access to, and quality of, palliative care services in Australia and is consistent with the goals of the National Palliative Care Strategy. Under the Program there are initiatives across six broad priority areas:

- Better access to medications for palliative care in the community.
- Assistance for families and increased support to other care networks.
- Education, training and support for the workforce.
- Increasing access to palliative care services.
- Supporting research into palliative care.
- Performance information development.

Objective 1.2 of the National Palliative Care Strategy is:

> To improve the knowledge and skills of families, carers and community groups so they can better support relatives, loved ones or individuals within the community who are dying, and work optimally through their bereavement.

This focus on palliative care in the community gave birth to the Caring Communities Program (CCP). This program was designed to improve the quality of palliative care in the community by assisting families, carers and health service providers to give better support to people who are dying. It included the following six objectives:

- To improve the knowledge and skills of families, carers and community groups so they can better support relatives, loved ones or individuals within the community who are dying, and to support them through their bereavement.
- To enhance community awareness of the role and benefits of palliative care in meeting the needs of people who are dying and their families.
- To improve awareness of a broad range of health care providers to the role of palliative care as an integral part of the health care system and their role in this area.
- To support the educational needs of the specialist palliative care workforce and primary health practitioners and enhance the skills of both groups in working collaboratively across professional boundaries.
- To support the coordination of care for the person who is dying and their family.
- To develop strong partnerships between palliative care service providers, other health service providers and the service system infrastructure to ensure the delivery of palliative care is geographically accessible and integrated across service delivery settings.

Tenders were invited in October 2002 for funding of between $50,000 and approximately $200,000 for those organisations with an interest in improving the quality of palliative care in the community. This opportunity stimulated a lot of interest from various organisations and approximately 270 submissions were received nationally. From these applications 37 projects were funded, totalling around $4.7 million over four years.

These 37 projects address several ‘themes’ associated with palliative care, including:

- Improving community awareness of palliative care.
- Supporting dying people and their families.
- Increasing awareness of palliative care as an integral part of the health care system.
- Delivering education to support professionals providing palliative care services.
- Creating effective partnerships between palliative care providers, other health service providers and health systems, to coordinate care for dying people.

Various groups were established or involved to oversee the development and implementation of the CCP. This included a National Reference Group (NRG), the Palliative Care Intergovernmental Forum (PCIF), Expert Evaluation Advisory Group (EEAG) and Palliative Care Australia (PCA).

2.2 Method of the national evaluation

In May 2003, following a competitive selection process, the Department of Health and Ageing (DoHA) engaged the Centre for Health Service Development (CHSD) at the University of Wollongong to undertake the national evaluation.

2.2.1 Evaluation framework

The CCP Evaluation involves the evaluation of the Caring Communities Program and the 37 different Projects that have been funded within the Program. To facilitate this, the CHSD National Evaluation Team (NET) developed an evaluation framework for both the program-level and the project-level evaluations. This framework was developed on the basis of the Commonwealth brief for the evaluation, and built on our previous experience in evaluating other projects. A draft framework was presented at the National Workshop in May 2003. Subsequent discussion and feedback from projects, the EEAG and the NRG was used to refine the framework so that it effectively represents the interests of both the CCP and the individual projects.

This framework was formally signed off by the Expert Evaluation Reference Group (EEAG) at its meeting on 2 July 2003 and then formally approved by the National Reference Group (NRG) at its meeting on 30 July 2003. The final framework included an additional key question area on dissemination – 'who did you tell?' – added as a result of the National Reference Group meeting on 30 July 2003.

The evaluation framework operates on three levels:

- Level 1 Impact on, and outcomes for, consumers (patients, families, carers, friends, communities)
- Level 2 Impact on, and outcomes for, providers (professionals, volunteers, organisations)
- Level 3 Impact on, and outcomes for, the system (structures and processes, networks, relationships)

A booklet describing the evaluation framework in detail was prepared by some of the NET members and published by the Australian Government Department of Health and Ageing[1] (Eagar, Cranny and Fildes, 2004).

2.2.2 Methodology

Evaluation of the CCP had formative and summative components. The NET were not impartial observers of the projects but played a capacity building role, developing a framework and tools for the evaluation, visiting the sites to discuss project plans and possible evaluation methods, attending National and State and Territory workshops and teleconferences and being available to consult as needed by email or telephone. Risk assessments were carried out and NET members intervened to provide extra support in projects deemed 'at risk' of failing to meet their objectives. The support and communications role played by the NET is described in the report, *Caring Communities: Report to the Australian Government on the national evaluation.*

Each NET member was assigned a number of projects to track and support throughout the CCP. Division of the projects into groups was based mainly on the location (State and Territory), but several projects involving Aboriginal and Torres Strait Islander communities in different States and Territories were assigned to a NET member with experience in working with Aboriginal people. In this way each NET member developed quite a detailed knowledge and understanding of a number of projects.

The process evaluation of the CCP encompassed the planning and selection processes, the management and progress of individual projects and the support available to them from within their auspice bodies and other stakeholders. This aspect of the evaluation included initial and ongoing reviews of documentation and the collection of qualitative and quantitative data on the ways in which the projects were chosen, established, supported, run and evaluated. We drew on a variety of data sources, namely:

- An initial review of project proposals (i.e. successful applications for CCP funding).
- A careful examination of every six-monthly progress report submitted by each project during the course of the CCP.
- Stakeholder interviews with PCA, DoHA and State and Territory Health Department officers at the beginning, middle and end of the CCP.
- Participation in, and evaluation of, two national workshops.
- A review of CCP-related documentation produced and held by DoHA central office.

[1] Eagar K, Cranny C and Fildes D (2004) *Evaluation and palliative care: a guide to the evaluation of palliative care services and programs*. Centre for Health Service Development, University of Wollongong ISBN 0 642 82472 X http://www.uow.edu.au/commerce/chsd/palliative_care.html

- A review of the final reports and other documents (e.g., manuals, evaluation reports) produced by each of the 37 projects.
- Analysis of the Sustainability, Capacity Building and Generalisability checklists completed by projects at the beginning, middle and end of their timelines.
- An exit interview with a representative of each project, usually the project officer.

More details on the data collection methodology, including the development of the toolkit, can be found in the report, *Caring Communities: Report to the Australian Government on the national evaluation.*

Some of the methods and sources used for the process evaluation also provided valuable data on outcomes, which were then assessed against the aims and objectives of the CCP and the national palliative care strategy.

Very large amounts of qualitative data were generated. The challenges of tracking, monitoring and analysing the data were met through the use of standardised templates for data collection and presentation and ongoing analysis throughout the course of the evaluation project. Results, as they became available, were presented in progress reports to the Australian Government.

NET members read their projects' six-monthly progress reports and extracted data onto a form. The data were then entered into an Excel spreadsheet and analysed by one NET member. The purpose of the analysis was to track the progress of each project in meeting the objectives set out in its project plan and to identify any projects in need of additional support. The reports also provided information on the prospects for sustainability, generalisability and capacity building from the projects and described dissemination strategies and results. This information was summarised in the NET's progress reports to the Australian Government at six-monthly intervals.

Templates were created for the semi-structured exit interviews with project officers and interviews with other stakeholders (e.g., DoHA officers in each State and Territory and in central office; State Health Department officers) at three time points in the CCP: beginning, mid-point and end. These interviews were usually conducted by telephone, although sometimes it was possible to take advantage of site visits or workshops to interview a stakeholder face-to-face. Notes were written or typed during the interviews and these were written up as soon as possible afterwards by the person who conducted the interview. The data were later extracted into Excel spreadsheets – one for the project officers' exit interviews, the other for the stakeholder interviews – which provided a set of thematic charts for qualitative analysis.

The framework method of qualitative analysis was used because it is systematic, allows an investigation of themes and issues within and between cases, and is appropriate for condensing and synthesising large quantities of data from interviews. The questions covered in the interviews were set out in columns to enable easy scanning and comparison of the answers given by different respondents (in rows). Analysis was conducted by several NET members and consisted of familiarisation with the data followed by identification of emergent themes. Patterns and clusters in the data were identified and interpreted. This approach was particularly valuable for examining the processes of individual projects (e.g., project planning and management) and the program (e.g., communication strategies) and forming hypotheses about the factors relating to particular kinds of project outcomes.

One of the deliverables of the evaluation was a brief summary of each project, covering the main evaluation questions at the project level, which were:

1. What did the project do?
2. How was the project evaluated and what outcomes were achieved?

3. What aspects of the project will continue (sustainability)?
4. What has been learned from the project (capacity building)?
5. Are the lessons useful for someone else (generalisability)?
6. Who was told about the project?

These summaries can be found in the report, *Caring Communities: a description of the 37 projects of a national palliative care program.* NET members created them by drawing on all the available data sources for each project, especially the projects' final reports, evaluation reports and progress reports. The resulting summaries are both descriptive and evaluative. This proved a useful way to synthesise very large amounts of information. The standardised headings and content in each cell of the summary table enabled a systematic analysis of themes and issues across projects.

Quantitative data from the checklists on sustainability, generalisability and capacity building completed by projects at three time points (beginning, middle and end) were entered into an Access database form and extracted into SPSS for analysis.

3 The impact and outcomes of the Caring Communities Program

In this section we present findings on the impact of the CCP for consumers, providers and the system (the three levels of the evaluation framework). Within these levels we summarise outcomes for the many target groups for CCP projects. It is assumed that the impact of the CCP consists of the combined outcomes of the 37 projects, plus any value added by the program management processes.

Using the framework for this evaluation five of the six objectives of the CCP focus on provider (Level 2) or system-level (Level 3) impacts: raising community awareness (Level 3), improving awareness of palliative care providers (Level 2), supporting the educational needs of providers (Level 2), improving coordination of care (Level 3) and improving partnerships between providers (Level 3). Many of the strategies across all CCP projects aiming for improvements at the provider and system levels have the potential to impact on consumers (Level 1) but only one objective – improving the knowledge and skills of families, carers and community groups – has a focus at that level. Not surprising, this emphasis is reflected in what projects did and what they achieved, resulting in only a small number of projects targeting consumers.

3.1 Level 1: Impacts on, and outcomes for, consumers

This section reports on outcomes at the level of consumers, who include palliative care clients, family members and other informal carers, as well as specific target groups such as people living in rural and remote communities, people who identify as Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD) groups, older Australians and dementia patients, and children and young people.

One project (QLD-3) established a counselling and support service for grieving children, young people and families; sought to raise awareness about the needs of this age group prior to and after a death, and aimed to develop a network of social workers and counsellors to support this work. A total of 178 people from 5 to18 years of age were supported by the service over a 19 month period, with almost three-quarters of the support related to the death of a parent. The service was found to be accessible and inclusive. Feedback from stakeholders indicated that the model of service provision was child-focused, inclusive, individualised, developmental and continuous, using a variety of creative and expressive methods.

One project in the remote community of Kalgoorlie (WA-3) aimed to develop a coordinated palliative care service (in an area where no such coordination had taken place previously) and enhance the delivery of palliative care. Satisfaction surveys were conducted annually and, although the numbers were small, indicated a high degree of satisfaction with the service by clients and carers.

Improved coordination was also the focus of another project in Western Australia (WA-5) which aimed to improve the continuity of care between hospice and community based services, improve the quality of care provided to patients/families at home and in the hospice and avoid potential inappropriate admissions to the hospice. The methodology used for the evaluation did not lend itself to identifying whether inappropriate admissions to the hospice had been avoided but satisfaction surveys (completed by 15 patients and 12 carers) focusing on the relationship between the hospice and community-based teams, and on admission and discharge processes, resulted in generally very positive feedback.

One project (VIC-5) tackled the important issue of advanced care planning and sought to make conversations on this subject a routine part of admission to palliative care or residential aged care facilities in rural and remote communities. The framework for the project was based on a program run by Austin Health, Melbourne. The project trained about 200 advanced care planning consultants to conduct such conversations, of whom more than half participated in the program.

The consultants described the benefits (e.g., improved communication among family members) and difficulties (e.g., finding an appropriate time to initiate ACP discussions) of the framework. Feedback from five patients and one carer was mostly positive and all patients were glad to have the opportunity to document their choices and were confident these would be respected.

Two projects focused on the needs of carers and included assessment of impact as part of project evaluation:

- Carer knowledge increased after each module of a carer education and support program, compared to prior knowledge, and remained higher four weeks after the education program (WA-4). After attending the program, carers were more confident about taking patients home to die.
- A one-day program for carers involving education, support and provision of resources, with follow-up support via telephone resulted in a variety of reported benefits, including improvements in dealing with the demands of their caring role, a better understanding of what palliative care is; and an improved acceptance of their own responses to the situation. All 15 carers who took part in the training showed an improvement in coping ability (NSW-9).

A number of other projects also targeted consumers. Although they originally planned to demonstrate improvements in patient and carer outcomes, they later changed course, did not build evaluation of patient/carer outcomes into their evaluation, or were unable to demonstrate any impact on consumers:

- The SEAM project in Queensland (QLD-4) was designed to improve services to patients and their families, either directly or indirectly, in a number of ways, including increasing the support available to patients and their families, providing education; and improving the coordination of care. During the course of the project it was decided that the value of SEAM lay primarily in coordinating services and providing referral when needed, with less emphasis on direct contact with patients. Evaluation focused on service providers and hence provided no data on patient/carer outcomes.
- A volunteer program (NSW-5) that (amongst other things) aimed to support carers by recruiting past carers to provide peer support but did not evaluate whether there was any impact on carers.
- The goals of one project (VIC-3) included improved integration of care for patients, family and carers and improved symptom management and psycho-social support of patients. However, no evidence was collected that either integration of care or symptom management improved, except that more GPs were tending to refer earlier and to use the agreed central referral pathway over the course of the project.
- One project (VIC-1) aimed to develop a model of support for employees affected by life-threatening illness, either themselves or as a carer. The support model was created during the project, with input from the project's reference group, 15 workplaces and about 22 palliative care providers. However, no pilot testing of the workplace model was possible and hence no evaluation of the model's effectiveness.
- A volunteer program in NSW (NSW-2) sought to increase support to carers (to improve their personal health and well-being), and reduce the social isolation of those with a life limiting illness. By project end it was too early to demonstrate an impact on either.
- One project (ACT-2) developed a resource kit consisting of two booklets, one entitled *Supporting a person who needs palliative care: a guide to family and friends*. The booklets were backed up by a community education package. There is no evidence regarding the impact of using these booklets on family and friends.
- One project (SA-3) had three main aims, of which one was to enhance the knowledge and skills of caregivers. Individuals involved in caring for a person with a life limiting condition were

interviewed. The interviews provided the project team with the opportunity to link people with appropriate services and help answer their questions in relation to palliative care. Recurring themes and phrases in the interviews were identified but no evidence on outcomes for carers were reported.

In summary, there is little evidence that the CCP had any direct impact on consumers (patients, carers, families). Four projects requested feedback from stakeholders or conducted satisfaction surveys of clients and carers, with very small numbers of respondents. Two projects collected more systematic data on the knowledge and coping skills of carers following interventions to educate and support them. Some projects did not build evaluation of impact on consumers into their evaluations, while others planned to do so but encountered serious difficulties (see Section 4.2.6).

In part, the lack of Level 1 impacts reflects the nature of the program, which emphasised capacity building among health care providers and palliative care volunteers, and forging partnerships within the sector. Projects addressing these priorities would be expected to have indirect, rather than direct, effects on the users of palliative care services.

3.2 Level 2: Impacts on, and outcomes for, providers

This section covers impacts on providers of palliative care services, including volunteers, primary and allied health professionals, aged and community care workers and palliative care specialists.

3.2.1 Volunteers

One project (ACT-1) targeted, amongst other service providers, volunteers as part of its goal to provide free education and training to service providers working with families who are receiving or may receive palliative care services. The education and training was focused on increasing participants' knowledge in palliative care. As a result of this project service providers and volunteers are working more closely together in ACT.

NSW-2 implemented a model of volunteer coordination and bereavement support for rural communities, addressing the needs of people with life threatening illness, their families and carers. Documentation sets for improved management and information systems for volunteers were developed. These included: volunteer training – mandatory; palliative care and bereavement training package (one for trainers and one for volunteers); volunteer recruitment; and volunteer coordination and ongoing management. The resources developed, such as the *Palliative Care and Bereavement Support Folder* can be used in other volunteer settings. As a result of the project eight recommendations were made to the local area health service to improve the volunteers systems and services and to provide ongoing support for project work.

NSW-5 recruited, educated and supported 10 Motor Neurone Disease (MND) volunteers providing support for people living with MND and their families in the Hunter, Newcastle and Central Coast communities. A *MND Volunteer Visitor Resource Manual*, *Volunteer Visitor* brochure and facilitators kit (power point presentations) were developed and published. A Bereavement Protocol and flyer was developed and implemented. This successful project has improved the capacity of the community by ensuring a skilled, supported and well-connected group of MND volunteers. The MNDA NSW family support staff have adopted the Bereavement Protocol.

NT-1 recruited, trained, coordinated and supported a pool of volunteers to work with community based palliative care services in Darwin and Katherine. The project also aimed to modify and/or develop educational resources for training volunteers that took into account some of the issues that are particularly relevant to the Northern Territory (i.e. multicultural and Aboriginal and Torres Strait Islander populations, people isolated from their families etc). The project was successful in training a large number of volunteers in the Darwin region. In fact, too many volunteers were

trained and there was some frustration expressed that they did not get the chance to do any palliative care volunteering.

QLD-2 enhanced community awareness of the role and benefits of palliative care through a network of volunteers based in workplaces, schools and the community. These volunteers, known as Palliative Access Links (PALS), were trained and resourced to provide information about palliative care services and links to other services.

QLD-5 established a model of interagency service delivery within which volunteers could be recruited, trained and supported. Guidelines and training materials were also developed to ensure the provision of uniform, quality volunteer support services offering services that support ill people to remain at home and maintain their independence. During the projects lifetime 25 volunteers completed the training and qualitative evaluation indicated high levels of satisfaction amongst both clients and volunteers.

One of the goals of SA-2 was to set up a Volunteer Support program on Kangaroo Island to help provide practical and emotional assistance for people who are dying either at home or in an institutional setting. Palliative care community education and awareness sessions generated a lot of interest in the local community to become involved in palliative care volunteering. In all 12 volunteers were recruited, trained and supported with a volunteer handbook, a volunteer program manual and an orientation handbook. All of these resources were created by the project and included relevant information about managing a volunteer care service, protocols, policies, management structures and legal responsibilities.

As part of its overall goal to increase the knowledge base of health professionals, key community agencies and the residents of the Southern Midlands Municipality of Tasmania, TAS-2 selected, trained and coordinated nine volunteers to provide support to clients in their own homes, specialist units and the local hospital. This volunteer service has been very successful in the local community and has created a lot of interest in matters relating to palliative care.

VIC-2 developed links and protocols to increase communication with the 17 health service agencies which auspice palliative care volunteer services in a local region of Victoria. In each of these health services volunteer coordinators were given management training to assist them in their coordination role. This training also included a workshop on submission writing to help build the capacity of the auspice agencies to seek funding for volunteer services. In addition, local volunteers were trained by qualified palliative care staff and several workshops were held focusing on health promotion in palliative care. This project was successful in improving communication between services and volunteers, helping provide a supportive framework for palliative care services in the local region.

3.2.2 Primary care and allied health professionals

Many projects focused on increasing professional awareness and understanding of palliative care, especially among health professionals from generalist services. The projects aimed to improve care for consumers by developing a workforce more aware and knowledgeable of palliative care.

Evidence of increased awareness and understanding was presented by at least 12 projects. A wide variety of methods were employed, including workshops, one-to-one training or individual placements, online and video resources and comprehensive education packages.

3.2.2.1 Workshops

One project originally planned to hold 12 workshops over a three-year period, providing training to health professionals in palliative care, grief and loss (ACT-1). Due to increased demand, 25 sessions were held which attracted 247 people. A workshop evaluation questionnaire was distributed at the end of each training session and was completed by 184 participants. A follow-up evaluation was posted out to participants two months after the workshop. Almost three-quarters of

respondents to the follow-up questionnaire believed the workshop had made a difference to their work, with many reporting an increase in sensitivity and insight or understanding of families' needs. From these responses it can be inferred that many participants did feel the workshop improved their skills in supporting patients receiving palliative care and their families.

An interactive educational strategy for primary health care providers in rural and remote communities involved one-day 'travelling workshops' delivered by palliative care specialists and one-on-one sessions for GPs (QLD-1). Education teams included medical officers, clinical nurse consultants and allied health professionals. Participants included therapists in aged and community care, pastoral care workers, volunteers, counsellors, Aboriginal and Torres Strait Islander health workers, allied health, nurses and GPs. The sessions were accredited by the RACGP and ACRRM so that GP participants could receive Continuing Professional Development (CPD) points for their participation. The evaluation revealed that, overall, there were statistically significant increases in palliative care skills, knowledge and practitioners' confidence in their management of palliative care patients, following education. At the four-month follow-up, 23 of the 38 respondents said they had treated one or more palliative care patients since education. Of these, 87% reported that education had a positive impact on their management of patients.

Service and health providers were provided with a half-day education program on carer needs, palliative care, loss and grief and available resources. Australian resources were used including an interactive CD ROM and video. In addition, case studies were discussed in small groups. There were 12 sessions conducted with a total of 142 participants attending, mostly from community settings. All groups completed pre- and post-course written questionaries. For service providers a fun quiz was also used, along with participant observation. Most providers indicated that they were better informed about palliative care, loss and grief and access to resources following the education. In addition, most reported they now had more confidence in dealing with their palliative clients, and loss and grief issues. Participants requested continuing education on these topics.

One project (NT-4) aimed to address gaps in palliative care education in the Alice Springs and Tennant Creek workforce. In order to achieve this, the project brought in a series of palliative care experts into the communities to deliver a series of workshops and seminars. An evaluation form was developed to find out the impact and usefulness of the education sessions and this showed that the knowledge of palliative care in the workforce had been raised. The project demonstrated the willingness of experts to share their knowledge and experience with remote practitioners and that practitioners found this education to be both useful and relevant.

Cultural diversity and awareness training was provided to primary health providers and Aboriginal health workers in a culturally diverse region of Adelaide (SA-4). Palliative care toolkit Tool 2.5 was used to assess the level of palliative care awareness amongst health professionals working directly with the Vietnamese and Italian communities. The evaluation results of the cultural awareness training targeted at Aboriginal health workers were extremely positive and described by one participant as 'the best in-service I have been to because I really felt it came from the heart.'

Education programs for health professionals occurred as part of a wide range of initiatives aimed at developing an integrated and cooperative palliative care service in Kalgoorlie-Boulder and surrounding regions of Western Australia (WA-3). The original education plan for the project focused on sending health care providers to Perth for training. However, it proved to be more beneficial and practical to purchase and deliver specialist education programs in Kalgoorlie. Education programs spread over a number of weeks proved more acceptable than (say) one three-day block. Once the optimal mode of delivery had been established, attendance at the education sessions was encouraging with positive feedback from participants.

3.2.2.2 Clinical placements

Another education initiative, aimed exclusively at GPs, was designed to promote a greater understanding of palliative care and to improve integration of care for patients, family and carers

(VIC-3). The key objectives were to improve symptom management and psycho-social support of patients, to improve networking and communication with specialist providers, to improve understanding by providers of the challenges and constraints on GPs providing palliative care to their patients and to increase opportunities for patients to be cared for in their setting of choice. A clinical attachment program was developed and adapted so that GPs could claim 48 CPD points for their part in the program. The administration of the CPD points was facilitated by an administrative officer to reduce the burden of GPs paperwork. Overall evaluation of the GPs' experience was extremely positive and indicated that they were more confident about their initial referrals and about pain management and the overall management of their palliative care patients. Results also indicated that GPs' referral patterns changed and that they passed on their knowledge to nurses, practice managers and other GPs.

3.2.2.3 Website and online resources

La Trobe University developed a website for Palliative Care Victoria aimed at developing professional awareness and understanding of palliative care (VIC-4). It was primarily targeted at health professionals (particularly GPs and community nurses) and those working in the field of palliative care. The site is targeted somewhere between information giving and education. It provides information but also access to resources that will educate. Evaluation was carried out at each stage of project development (pre-development, beta site development, beta testing, launch/sustainability). Lessons learned at each stage guided the development and implementation of the next stages. A satisfaction survey has been built into the 'live' website. In addition, the functionality of the website will be monitored through statistical analysis of site visitors (hit rates, navigation and points of access and exit).

3.2.2.4 Satellite television

Another CCP project demonstrated that satellite television programming is an effective medium for residential aged care staff education in rural and remote settings (NSW-7). The evaluation showed reduced numbers of transfer rates out of residential aged care facilities and into specialist palliative care services as a direct result of staff in ARV becoming more knowledgeable about palliative care. It is also a relatively cost effective and efficient way of training at a cost of approximately $50 per staff member.

3.2.2.5 Education packages

A model of intensive palliative care education implemented in residential aged care improved the skill and confidence of nurses to manage pain, and improved residents' outcomes (NSW-6). The model was developed and implemented in one residential aged care facility in the greater Western Sydney area. It involved education; clinical support; *Family Information* Booklet; pain management flowchart and use of pain assessment tools (Abbey Pain Scale and NOPPAIN); and a learning package about pain. Experiential learning using their own residents as case examples proved more successful than formal education sessions. Residential aged care staff also improved their confidence and skills. Nurses from the residential aged care facility reported that GPs had improved their skills as a result of the project intervention.

A self-directed learning package was developed for use by care workers to improve their knowledge and skills for delivering care to clients with a life-limiting illness (SA-1). The education package consists of guidelines, a case study, four elements, evaluation forms and further readings. The development of this package was supported by a wide variety of stakeholders. Of the 53 people that completed the package, 88% indicated that it was useful, beneficial and user friendly.

In the course of developing a new, collaborative, approach between specialists and primary care providers in rural Tasmania (TAS-1), primary care providers developed a greater understanding of palliative care and the services available in their area.

An education resource for health care workers and members of the community on issues surrounding palliative care and dementia was developed (ACT-3). Formal evaluation results are not yet available.

3.2.3 Specialist palliative care professionals

A few CCP projects reported outcomes for specialist palliative care staff, in terms of increased understanding of special target groups (dementia patients, children and young people) or the roles of primary health staff.

A collaborative approach was developed between specialist and primary palliative care providers in rural communities in Tasmania (TAS-1). State-wide standards and clinical protocols for referral, intake, admission, allocation and intervention were developed, together with a consistent approach to assessing client needs and care planning.

Another project aimed to increase and sustain the scope of support provided by palliative care teams for dying and bereaved children and their families (NSW-3). This was achieved through the development of a training manual called of '*Kids' Grief: A handbook for group leaders'*. This manual was created with consultation with subject experts who conducted clinical reviews of the manuals content. Focus groups were also held to review the manual's content. The net result is an informative product that has national and international relevance.

Similarly, a project officer with specialist knowledge and experience of working with bereaved children and young people has been able to share her expertise with health professionals, including palliative care specialists (QLD-3). The project has contributed to knowledge about how to work effectively with bereaved children and young people by documenting and disseminating its model and methods. Palliative care workers in specialist and community-based services have indicated that they value the service and believe it is needed.

Evaluation results from palliative care staff involved in a new model of care for end-stage dementia patients show that care services are now better able to undertake care of people with severe or end stage dementia (NSW-6). As a result of the intervention, people in the final stages of dementia are now accepted as appropriate for referral to palliative care services in the local area.

A project that developed cultural diversity protocols for palliative care demonstrated the importance of training mainstream health workers to be culturally competent and to work in partnership with Aboriginal and multicultural services (SA-4). The project evaluation concluded that only when these workers understand the unique needs of these communities will access to these services improve for these groups. Key to this goal is to build strong relationships between mainstream palliative care peak bodies and services with key Aboriginal and multicultural stakeholders.

3.3 Level 3: Impacts on, and outcomes for, the care delivery system

Some of the project outcomes reported above also have implications for care delivery. For example, volunteer services that provide best-practice training and support will be more effective than other services, because they will be more likely to develop and retain a group of highly skilled volunteers. Thus, projects that developed volunteers' skills and knowledge are likely to have indirect effects on the system. This section of the report focuses on the broad, system-level impacts of the CCP.

3.3.1 Knowledge and skills of carers and communities

Education and support for carers may have system-level impacts if it results in changes to the place of death for some patients who would prefer to be cared for at home. Although this was the goal of several CCP projects that targeted carers, none actually evaluated whether these system-level changes occurred. Nevertheless, they were able to demonstrate an intermediate outcome:

that training programs could provide carers with the skills and confidence they needed to care for their patients at home.

An education and support program for caregivers was designed to provide caregivers with practical skills in caring for someone at home and increase their awareness of existing community resources. Carers provided positive feedback and indicated that, after attending the program, they were more confident about taking the people they are caring for home to die (WA-4).

Another project provided education and support to carers to enable them to better manage the demands of caring at home and to better cope with their own grieving and adjustment process once caring has ended. All carers reported benefits from the training, including improvements in dealing better with the demands of their caring role (NSW-9).

Carers of deceased cancer patients were interviewed during a population-based retrospective cohort study (NSW-8). The project made ten recommendations relating to meeting carers' information & support needs and health care services issues. Carers found it hard to access information and one recommendation was that palliative care consumers need a 'one stop shop' for information.

Two other CCP projects also targeted carers but did not provide evidence of impacts. Carers were among 75 people who were interviewed during a project that aimed to enhance the knowledge and skills of caregivers in order to help them better cope, and to provide better care for loved ones. Interviews provided the project team with the opportunity to link people with appropriate services and to help answer their questions in relation to palliative care (SA-3). Another project used carers as partners in delivering education. The project invited past carers of people with motor neurone disease (MND) to attend the volunteer training program and shared their experiences of caring (NSW-5).

A number of projects reported difficulties in recruiting carers.

3.3.2 Community awareness and understanding of palliative care

Raising community awareness is a necessary precursor to building community capacity to provide support for people receiving palliative care, their families and friends. There were a number of projects which specifically aimed to raise community awareness and understanding of palliative care and could therefore have system-level impacts. The following projects reported evaluation outcomes relating to community awareness:

- A resource kit promoting palliative care, explaining the role of the palliative care team and providing a directory of services was developed and trialled at education sessions with four community groups Overall, positive feedback was received from all presentations and further refinements to the resource kit were made as a result of feedback from these sessions (ACT-2).
- The PALS program targeted the general community as well as ill people and their carers. Three training sessions were conducted, which led to the recruitment of 40 PALS volunteers based in workplaces, schools and the community. By the end of the project, the PALS volunteers had achieved over 700 community contacts via group presentations, individual requests, displays and information stands at workplaces and community events. A community awareness survey was conducted in July 2003 to identify baseline information. A total of 96 people were contacted by telephone, 90 completed questions 1 and 2. Of these, 78 were then posted the remaining questions, 67 returned them. Survey results indicated a lack of understanding in the community about palliative care. In March 2005 30% of the original participants were surveyed again, and palliative care knowledge had increased (QLD-2).

- Community focus groups were conducted and a Palliative Care Awareness survey tool was used to judge the impact of a project designed to improve the capacity of communities to care for someone with a life threatening illness by implementing a model of volunteer coordination and bereavement support (NSW-2).
- A bookmark, *Know Someone Who is Grieving*? was developed for distribution to small businesses and communities in the local area. This resource provides tips on how to respond helpfully to bereaved people and a list of relevant local resources. A brief survey (five questions) was distributed to gauge how local businesses interacted with bereaved customers and asked what the project could do to support them in terms of information or education. Of the 97 questionnaires distributed, 78 (80.4%) were returned (NSW-4).
- Palliative care community education and awareness sessions were held in main towns on Kangaroo Island (SA-2). These community education sessions were evaluated using a survey designed by the project coordinator. The response rate from the community sessions was good (30 completed surveys from 33 attendees). Respondents stated that the sessions were well presented and informative.
- In another project (SA-3) seven community education sessions tailored to the local community were presented in the targeted areas and evaluated with a questionnaire. Results indicated that the majority of respondents were satisfied with the information provided and many expressed an interest in attending future similar sessions. During the life of the project it is estimated that 1,500 individuals have been involved in the project through information sessions, and community partnerships and engagement.
- Baseline data were collected on the understanding of palliative care in remote communities of Western Australia (WA-1). This information was used to monitor the progress of the project and to provide feedback to communities and staff. The project has demonstrated that it is possible to raise awareness of palliative care in remote Aboriginal communities, despite considerable barriers due to remoteness and communication..
- A project (SA-4) evaluated community awareness (at a consumer level) in three communities (Aboriginal, Italian and Vietnamese). Overall, the consumer evaluation revealed a general lack of knowledge of palliative and bereavement care within each of the communities. This was identified as a barrier for accessing relevant services. Therefore, there is a need to educate the Aboriginal, Italian and Vietnamese community about palliative care and bereavement services in order to build their capacity to access more culturally appropriate services.

Some projects provided indirect evidence of their impact on community awareness. For example, one project (NSW-1) developed a positive relationship between the Area Health Service and the local Elders' Group. This resulted in ongoing requests for health providers to attend the local Elders' Groups to discuss issues such as, 'What is palliative care and how do we access it?'.

A few projects identified successful ways to raise awareness. For example:

- A Tasmanian project (TAS 2) assessed community awareness of palliative care prior to conducting community forums and then reassessed three months later. The evaluation revealed that overall participants' knowledge of palliative care had significantly increased after the forum. The biggest impact in terms of raising awareness about the project came from appearances on local radio and targeted mail outs of information leaflets.
- Another project (Vic-3) used a promotion strategy where they met the local MPs to tell them how the grant money had been used successfully in the community. This resulted in an article in the Frankston Bulletin, published by the local Federal MP and circulated to all households in the electorate and other Federal MPs.
- A project in Darwin (NT-1) put a great effort into dissemination activities including displays and posters during palliative care week, newspaper articles, radio interviews and posters. As a result of this, the Darwin community appeared to be quite well informed about palliative care and the role of volunteers.

- In another project (QLD-3) the coordinator has been successful in raising awareness, especially within schools, of children's bereavement issues. The success of this dissemination strategy is reflected in the variety of referral sources, including 15% by word of mouth through family friends or colleagues.
- An innovative strategy for palliative care health promotion involved training a group of volunteers and professionals and setting up a committee to invite and assess applications for small grants. Community groups were encouraged to apply and the application process was kept very straightforward. As a result of this initiative, many small local initiatives were funded, with the community groups matching the grant funds (VIC-2).

In addition, all projects were asked to keep a log of their dissemination activities (see Section 3.7). Many of the dissemination activities such as newspaper articles, media releases or radio interviews would have contributed to raising community awareness about palliative care.

3.3.3 Care coordination for people who are dying and their families

There were several projects that focused primarily on improving the coordination of care for people who are dying and their families.

Two projects (TAS-1 and WA-3) were funded to develop integrated palliative care services for their regions. One of these projects (WA-3) received further funding as part of the Rural Palliative Care Program, the final results of which will be available in April 2007, and the Tasmanian project developed close links with a Rural Palliative Care project in the North West of that State. Interim findings from the Tasmanian project show that since the project commenced the proportion of clients accessing the community palliative care service throughout the state has shown a consistent and sustained increase. Greater awareness of the role of the specialist service has resulted in more referrals from primary care providers. The number of out-of-hours contacts from primary health care providers has also increased. The model provides a framework for the specialist palliative care service to support primary care providers with advice, information, resources and education.

The WA-3 project established a palliative care service, and in the two years 79 referrals were received. The project coordinator managed both the project and the palliative care service. Therefore, the coordinator position was seen as critical to the ongoing maintenance of the service. Through submissions to the regional health authority, funding has been secured and a coordinator position established. The challenge has been to enhance GP involvement in the palliative care service. The results indicate that a model of palliative care based on a multidisciplinary team that meets on a regular basis, with good support from GPs and other health care providers, is suitable for communities of a comparable size.

A registered nurse was employed to carry out liaison and referral work in palliative care (QLD-4). An independent evaluation confirmed that the role of the SEAM (Support, Education, Assessment and Monitoring) service nurse had evolved to mainly being involved networking, capacity building and support of service providers, advising health professionals on patient care, and providing resources to GPs, practice nurses and some patients. This liaison and support role was highly valued by many service providers and health professionals. SEAM has succeeded in making GPs more aware that a palliative approach may be appropriate for a wider range of patients than they had previously considered.

Some projects focused on care coordination for a specific part of the care delivery system, such as volunteers. These are described above (Section 3.2.1).

Other projects worked on improving the continuity of care between services providing palliative care and other services. For example, education of service providers has improved care coordination between a specialist palliative care service, residential aged care and general practices for people with end-stage dementia (NSW-6). Clinical attachments, file sharing,

introduction of a common assessment tool and attendance at team meetings were key strategies in a project that improved links between an inpatient hospice and a community-based palliative care service (WA-5).

One project aimed to formalise a coordinated bereavement care service (NSW-4) for Queanbeyan, Yarrowlumla and Tallaganda (QTY) Shire areas. It appears, however, that rather than coordinate a bereavement service, the project focused on raising awareness of bereavement issues and increasing access to information and resources.

Another project (VIC-3) has built on its evaluation findings, which highlighted the lack of support available for palliative care in aged care facilities. These data were used to support a successful application for funding to employ a palliative care nurse to assist in the coordination of care for residents in aged care facilities.

The CCP has been successful in funding projects that have effectively improved the coordination of care. It appears that the sustainability of these projects relies on the establishment of ongoing positions responsible for coordinating the palliative care.

3.3.4 Accessible and integrated care through strong provider partnerships

The CCP, by its very nature, has strengthened the partnerships within the palliative care delivery system and broader systems such as health (aged care) and education (universities).

Most projects formed governance or steering committees with membership from a wide range of partners. These partners were selected to manage and/or advise and support the project. In addition, many projects selected partners as part of their sustainability strategies. That is, they selected partners from the beginning of the project that may assist in sustaining project elements at the end of the funding.

There were a number of projects that aimed, as part of their project plan, to develop and or enhance accessible and integrated care through strong provider partnerships. Numerous projects reported impacts on provider partnerships but relatively few provided evidence of these impacts. The following section will highlight those projects with relevant evaluation findings.

Care integration was enhanced by establishing provider partnerships. In a rural community in Tasmania, one CCP project fostered collaboration between specialist and primary care providers, helping to identify the roles and responsibilities of each group (TAS-1). Similarly, a project based in remote Aboriginal communities in the Kimberley liaised with local community institutions such as nursing homes, clinics and community government councils and developed a network of local support systems and partnerships with these agencies. This liaison role has been incorporated into the community palliative care program, which means that it will continue after funding has ceased (WA-1).

A number of projects formed new working or consultation groups involving several organisations which have continued after the end of the project. For example:

- One project (SA-4) aimed to increase collaboration between specialist palliative care providers and primary health providers, Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse (CALD) organisations/agencies to ensure there is coordinated and culturally appropriate bereavement care. Evaluation of the local palliative care system was conducted using Tool 3.1. Considerable effort was made in building relationships with key bodies and stakeholders in each community. The working group of palliative care and Aboriginal peak bodies is still meeting, focusing on the needs of Aboriginal palliative care.
- Another project (ACT-1) formed a Bereavement Support Network, and this group attended by up to twenty organisations, continues to meet bi-monthly.

- Collaborative partnerships between dementia care and palliative care services have helped ensure referral between these services (ACT-3). As a result of these partnerships and the education provided by the project, people with dementia are better able to stay within the same residential aged care facility and still receive quality end-of-life care.
- Specialist information on the bereavement needs of children and young people was provided to a network of social workers and palliative care counsellors in the Brisbane area. This network was developed and facilitated by the project officer and now meets quarterly (QLD-3).
- The advisory group for the project (WA-3) has continued beyond the life of the project, in part due to support from the associated Rural Palliative Care project. The work done in engaging the local Aboriginal and Torres Strait Islander community, particularly the use of a formal arrangement with an Aboriginal and Torres Strait Islander organisation to provide support and liaison, provides useful lessons for communities with a sizeable Aboriginal and Torres Strait Islander population.
- Palliative care experts were flown in to provide workshops for health care providers in the Alice Springs and Tennant Creek regions. As a result, a network of providers has formed and is actively involved in lobbying for palliative care in the community. This group has secured on-going funding for palliative care projects in Alice Springs (NT-4).

The success of other projects was enhanced by the activities of partner organisations in promoting and/or sharing information across the system. For example:

- A reference group was formed to oversee the design of a palliative care resource kit and community education packages. Members of the reference group acted as ambassadors for the project, promoting the resources within their jurisdictions, which included the general community, the specialist palliative care sector and aged care (ACT –2).
- Partner organisations created networking opportunities for a project that developed a volunteer palliative care support service (QLD-5).
- One project (TAS-2) has created positive linkages and sharing of resources with the local specialist palliative care service and the Hospice Care Association.

Other project partners contributed by supporting 'in-kind' work on the project. In one case, the area health service management allowed nurses to become involved in the project work, and the project also benefited from the goodwill of the directors of nursing of local residential aged care facilities (NSW-6).

The ongoing work of some projects has been sustained by one or more of the partners:

- One project reported that partnerships between three organisations were the cornerstone of its success. One partner funded a coordinator position for the next two years. Another is providing ongoing training for the volunteer training program (NSW-2).
- Another project (NSW-6) reported their major achievement was to build capacity of area health service community-based staff so that people in the final stages of dementia are now accepted as appropriate for referral to palliative care services.

The development of partnerships also provided opportunities to raise awareness and increase knowledge of the participating members. Support and advice received from the university partner of one project was valuable in helping to develop research and evaluation skills of area health staff (NSW-6). Another project (NSW-8) has led to new collaborations with the NSW Central Cancer Registry (CCR). In a project that supported and educated carers (NSW-9), two Commonwealth Carer Respite Centres (CCRC) received training resources for staff and carers in palliative care, including loss and grief. In addition, they were trained by Carers NSW and obtained skills in tele-

groups (using the phone as a tool for group support). Staff at Carers NSW become more aware of palliative care, as a result of hosting the project.

Several projects used not only provider partnerships to achieve their project aims, but expanded to include community partners too. For example:

- One project (SA-2) achieved the development of a vision for palliative care on Kangaroo Island. This has been achieved in part as a result of the great support networks that have been developed along the way between the community, professional staff, carers, volunteers and off-island specialists.
- Another project (SA-1) developed and evaluated a self-directed learning package for use by care workers to improve their knowledge and skills for delivering care to clients with a life-limiting illness. The development of this package was supported by a wide variety of stakeholders.
- A project (VIC-1) created a support model for life-threatening illness in the work place, with input from the project's Reference Group, plus 15 workplaces and about 22 palliative care providers (members of Palliative Care Victoria). Relationships have been built and maintained through the consultation process (e.g., between PCV and the Victorian Chamber of Commerce and Industry).

There was one project (NT-3) where improved partnerships did not occur, possibly because some of the service providers were not adequately consulted prior to the project being implemented. This project demonstrates the need to ensure the support of all key agencies before starting.

3.4 Sustainability, Capacity Building and Generalisability

Sustainability is defined, for the purposes of this evaluation, as aspects of a project's goals and objectives that may continue beyond the life of the CCP. An assessment of the long-term impacts of the CCP is beyond the scope of this evaluation, which concludes a few months after the last project has ended. Nevertheless, some information about possible outcomes in the longer term is available from the sustainability checklists and from exit interviews and project progress and final reports, which have been integrated in the project summaries.

Capacity building is defined as a project's ability to develop skills and knowledge about palliative care in the community. This was a major focus of the CCP, and many of these kinds of outcomes are reported above, but the checklists and project summary data provide additional specific information about the lessons learned and the partnerships created within the community and the health care system.

The concept of generalisability refers to whether lessons learned from a project could be useful to others. Project officers were asked to judge whether the lessons learned from their project could be useful in other settings. These lessons varied from information specific to palliative care and local needs to more general knowledge about successful approaches and pitfalls, for example, in project management or community engagement.

In this section we present quantitative data from the sustainability, capacity building and generalisability checklists and qualitative data derived from the project summaries.

The checklists were used to assess the system and organisational level impacts of projects. All project officers were asked to complete these tools at the beginning, middle and conclusion of their projects, with the exception of projects lasting 12 months or less, which completed the tool only at the beginning and end points. The checklists also had a section in which project staff were asked to write about their strategies for sustainability, capacity building and generalisability. This was treated as an optional section and the response rate was poor. However, much of this information

was duplicated elsewhere in documentation that was ultimately used to create the project summaries, so it is effectively included in the qualitative analysis reported below.

More than 70% of projects returned the first round of checklists, but response rates declined over time (see Table 1). Despite reminders by email and telephone, less than one third of the projects completed the tool at all three time points. Accordingly, the whole data set was also examined, and responses to some questions differed markedly when projects with and without complete data were compared, as discussed below. No statistical tests were conducted due to the small sample sizes, so while these comparisons suggest some reasons for non-completion of the checklists, they should be treated with caution.

Table 1 Response rates for checklist tools at three time points

Checklist	Initial	Midpoint	End	All three
Sustainability	26 (70.3%)	24 (64.9%)	22 (59.5%)	11 (29.7%)
Capacity Building	21 (56.8%)	24 (64.9%)	21 (56.8%)	10 (27.0%)
Generalisability	26 (70.3%)	24 (64.9%)	21 (56.8%)	11 (29.7%)

3.4.1 Sustainability

One of the major reasons for using the sustainability checklist was to detect changes in sustainability issues over time. It was hypothesised that during the course of the project there would be a move from less certainty to more certainty (ie., more 'yes, fully' answers) as strategies and structures to support the project's sustainability were put in place. This is evident in the data for two of the three sections in Table 2 (factors in project design and implementation, and factors in the broader community).

Projects that completed the tool at all three time points had increasing success in engaging stakeholders (Q1, Q10, Q11) and demonstrating outcomes (Q2). As time passed, more projects were able to acknowledge the real or in-kind support provided by the host organisation (Q3). On the question of funding (Q4), there was an abrupt change at the end as five projects secured their positions, four others were reasonably certain of continuing and only one remained in doubt. Initially, these 11 projects had been very cautious about their prospects: none indicated that funding had been 'fully' secured. In contrast, the whole data set shows that six of the 26 project officers who completed the initial tools claimed at the start that they had secured future funding. This suggests that some project officers were initially confident about sustainability but did not submit final data, possibly because these plans did not come to fruition.

Responses to questions about the organisational setting of the projects did not change much over time. From the outset, most project officers were convinced that the organisational settings of their projects would support and promote their survival. On the whole, they remained very positive about the maturity and stability of the host organisation (Q5), its ability to innovate (Q9), and the compatibility of the project with the mission and activities of the host (Q6). In most cases they felt their projects were well integrated into the host organisations (Q7) and there were no internal threats or rivals (Q8).

Table 2 Responses to Sustainability Tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points)

No	Item	Timing	Yes, fully	Yes, partly	No	Don't know	N
Project design and implementation factors							
1	People with a stake in the project - funders, administrators, consumers/beneficiaries, other agencies – have been aware of the project and/or involved in its development	Initial	3	8	0	0	11
		Mid	6	5	0	0	11
		End	9	2	0	0	11
2	The project has shown itself to be effective. Effects are visible and acknowledged	Initial	1	0	4	6	11
		Mid	2	7	0	2	11
		End	5	6	0	0	11
3	The organisation which you intend to host the project in the future has been making some real or in kind support to the project in the past	Initial	3	5	3	0	11
		Mid	5	4	2	0	11
		End	8	2	0	1	11
4	Prospects for the project to acquire or generate some additional funds or resources for the future are good	Initial	0	1	1	9	11
		Mid	0	4	2	5	11
		End	5	4	1	1	11
Factors within the organisational setting known to relate to the survival of a project							
5	The organisation that you intend to host the project in future is mature (developed, stable, resourceful). It is likely to provide a strong organisational base for the project	Initial	8	1	0	2	11
		Mid	9	1	0	1	11
		End	10	0	0	1	11
6	The mission of the project is compatible with the mission and activities of the intended host organisation	Initial	9	2	0	0	11
		Mid	9	1	0	1	11
		End	9	1	0	1	11
7	Part of the project's essential 'business' is integrated into other aspects of the host organisation eg. in policies, practices, responsibilities etc. That is, the project does not simply exist as an entirely separate entity	Initial	8	3	0	0	11
		Mid	9	2	0	0	11
		End	8	2	0	1	11
8	The project is well supported in the organisation. That is, it is not under threat and there are few rivals in the organisation who could benefit from the closure of the project	Initial	8	1	1	0	11
		Mid	9	1	0	1	11
		End	8	2	1	0	11
9	The intended host organisation has a history of innovation or developing new responses to situations in its environment	Initial	8	2	0	0	11
		Mid	10	1	0	0	11
		End	9	1	0	1	11
Factors in the broader community environment which affect how long projects last							
10	There is a favourable external environment for the project, that is, the values and mission fit well with community opinion, and the policy environment	Initial	5	5	0	1	11
		Mid	7	3	0	1	11
		End	9	2	0	0	11
11	People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	Initial	2	2	1	5	11
		Mid	4	7	0	0	11
		End	5	3	0	3	11

The project summaries indicate that 10 of the 37 CCP projects have someone continuing in the project officer position or a similar role, sometimes with reduced hours of work. Of these continuing positions, five involve the coordination of volunteer services. One project (NSW-2) has secured funding for a two-year pilot 'navigator/volunteer coordinator' position from the NSW Cancer Council. This dual role will assist people with cancer to find appropriate information and links to service providers as well as providing volunteer support. The Motor Neurone Disease Association in the Newcastle/Hunter region of NSW is continuing to fund a regional advisor to support the volunteers recruited during the project (NSW-5), run the education program again and recruit more volunteers. The pool of volunteers trained in Darwin (NT-1) will be supported through the new hospice at the Royal Darwin Hospital. On Kangaroo Island (SA-2), a 0.1 FTE position has been created to coordinate volunteer services and the protocols and procedures adopted by the project have been adopted by the local health service. Funded coordination of palliative care volunteers has been identified as a priority in the Hume region of Victoria and the regional palliative care service has resourced a position to provide guidance and support to volunteer services (VIC-2).

Facilitators or coordinators continue to be employed by five other former CCP host organisations (TAS-2, QLD-3, VIC-5, WA-3, WA-4). The effectiveness of these positions depends in part on the availability of additional funding to support their work; for example, for new equipment items (TAS-2), training materials (VIC-5), infrastructure and publicity (QLD-3) and respite services for carers wishing to undertake training (WA-4). For those in continuing positions, their expertise and experience is a considerable asset and their loss a potential threat to long-term sustainability.

Two further projects will continue because their activities have become embedded in the services provided by their host organisations (WA-1, WA-5). For example, certain features of one project such as joint clinical team meetings, use of an admission assessment tool and file sharing between home care and hospice workers have become part of day-to-day practice (WA-5).

Eight projects have been successful in obtaining new funds, which will be used to continue or expand their activities. Sources include the second round of the Local Palliative Care Grants Program, State government health departments and small grants from non-profit organisations. A number of 'spin-off' projects have been developed and funded, often using evidence from the evaluation process to support the applications. In this way the CCP has contributed to continuing service development in areas such as:

- Aboriginal health worker training (WA-1)
- education and support for carers (NSW-9, WA-1, SA-3)
- enhancing the knowledge of primary care providers and helping build links to palliative care specialists (QLD-1, NT-1)
- support for palliative care in residential aged care facilities (VIC-3)
- communication between palliative care services (VIC-4)
- improving the knowledge of families and aged care nurses about palliative care for dementia patients (launch and evaluation of a booklet; developing care pathways) (NSW-6)

At the time of writing this report, four CCP projects had applied for further funding but the outcomes of their applications were not yet known. A project that provided education to health professionals in remote areas sought funds to continue this outreach program and to employ someone on a permanent part-time basis to manage it (QLD-1). A project that developed a model using volunteers to enhance community awareness sought funds to expand to other areas (QLD-2). A project that employed a nurse to enhance care planning and coordination sought funds to continue the position (QLD-4). A project that established a palliative care volunteer workforce with specialist training, resources and support within a larger volunteer service sought donations and

sponsorship from large organisations, along with funding from the Australian Government's Home and Community Care program (QLD-5).

A huge number and range of resources were developed by CCP projects. At least 17 projects have strategies in place to ensure these resources will continue to be available, promoted and (when necessary) updated. More details on these resources are provided in the next sections.

3.5 Capacity Building

Respondents were reasonably confident that design and implementation aspects of the projects would promote capacity building in palliative care, with modest improvements over the course of the program (see Table 3). Most projects were able to build awareness of the project among stakeholders (Q1) and establish links with other organisations (Q2). Most officers believed their projects had provided some leadership in palliative care in their communities, although this did not change over time (Q3), and most projects had at least partial success in engaging the local media in promoting palliative care issues (Q5).

Responses to Q4, which addresses resolution of conflicting interests, were more mixed. At the outset, many had answered 'don't know' to this question, possibly because they had not yet identified areas of potential conflict. By the end about half of the officers felt they had been somewhat successful in resolving conflicting interests in palliative care locally.

All projects were able to report that formal or informal training had been provided to people whose skills would be retained within the local area (Q6). This represents the realisation of a major goal of many of the projects.

By the close of the CCP, all but one of the project officers indicated that their organisation had generated and supported the building of community skills and knowledge in palliative care (Q8). About half of the project officers indicated throughout the program that there was someone in a senior position, other than the project director, who would advocate for the project at high levels within the host organisation (Q10). There was partial success in directing more resources to palliative care (Q9) and establishing formal links (e.g., policies) with other organisations (Q7).

Some broader community support for the projects was present at the outset but this did not change systematically over time. By the end of the program, there was still a considerable degree of uncertainty about community engagement, as indicated by the relatively large numbers of 'no' and 'don't know' answers and the small number of projects that indicated that community support had been fully achieved. Nevertheless, many projects had benefited at least partially from the work of community coalitions (Q11), community leaders (Q13) and other members of the community (Q14) in appraising, advocating and promoting palliative care services. There was some movement towards greater cohesion in the palliative care sector, with community coalitions and organisations sharing a common view of services (Q12) and/or coming together for promotional events (Q15). Most project officers believed community members would advocate for the project should it be threatened (Q17). Responses indicated that client and/or carer involvement in running palliative care services had been only partially achieved (Q16), probably because this was not an aim of most projects.

Table 3 Responses to Capacity Building tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points)

No	Item	Timing	Yes, fully	Yes, partly	No	Don't know	N
Project design and implementation factors							
1	People with a stake in the project - funders, administrators, consumers/beneficiaries, other agencies – have been aware of the project and/or involved in its development	Initial	2	8	0	0	10
		Mid	5	5	0	0	10
		End	7	3	0	0	10

No	Item	Timing	Yes, fully	Yes, partly	No	Don't know	N
2	People involved with the project have been able to establish links with other organisations and providers of palliative care in the community	Initial	3	3	2	1	9
		Mid	5	5	0	0	10
		End	6	3	0	1	10
3	People involved with the project have taken a leadership role in the local community with regard to palliative care	Initial	5	3	1	1	10
		Mid	4	5	1	0	10
		End	5	5	0	0	10
4	People involved with the project have been able to resolve conflicting interests in the area of palliative care in the community	Initial	0	3	0	6	9
		Mid	1	4	2	3	10
		End	2	3	3	2	10
5	This project has been able to engage the local media in promoting relevant palliative care issues	Initial	2	0	7	1	10
		Mid	3	3	4	0	10
		End	4	4	2	0	10
6	The project has involved formal and/or informal training of people whose skills and interests are retained in the project or its immediate environment	Initial	1	3	5	1	10
		Mid	4	4	1	1	10
		End	7	3	0	0	10
Factors within the organisation's setting that to relate to capacity building							
7	This organisation has been able to establish agreed policies or memoranda of understanding with other organisations regarding the provision of palliative care services in the community	Initial	0	3	3	4	10
		Mid	2	2	4	2	10
		End	2	3	5	0	10
8	This organisation has generated and supported community skills to direct, provide, lead or otherwise contribute to the provision of palliative care services in this community	Initial	0	8	0	2	10
		Mid	3	7	0	0	10
		End	2	7	1	0	10
9	More organisational resources have been directed to the area of palliative care services in this community	Initial	0	3	3	4	10
		Mid	1	5	2	2	10
		End	2	5	2	1	10
10	There is someone in authority or seniority, other than the director of the project itself, who is an advocate for the project at high levels in the organisation	Initial	5	2	2	1	10
		Mid	6	4	0	0	10
		End	6	2	2	0	10
Factors in the broader community environment which affect the community's capacity to support the provision of palliative care services							
11	Community coalitions have formed to promote and advocate for palliative care services in this community	Initial	3	2	1	4	10
		Mid	3	3	2	2	10
		End	4	2	3	1	10
12	Community coalitions and organisations have a shared view of what comprises palliative care services in this community	Initial	1	3	0	6	10
		Mid	2	4	1	3	10
		End	1	6	2	1	10
13	Key community leaders have engaged in critical appraisal of the need for palliative care services in this community	Initial	3	3	1	3	10
		Mid	2	5	1	2	10
		End	1	5	2	2	10
14	Community members have taken a leadership role	Initial	1	4	2	3	10

No	Item	Timing	Yes, fully	Yes, partly	No	Don't know	N
	to promote palliative care services in this community	Mid	2	5	2	1	10
		End	2	5	3	0	10
15	Community events have occurred to acknowledge, promote or provide funds for palliative care services	Initial	1	6	1	2	10
		Mid	2	6	1	1	10
		End	1	7	2	0	10
16	Community members directly involved in or affected by palliation are actively engaged in the oversight of the development, provision or management of palliative care services in this community	Initial	2	5	1	2	10
		Mid	2	5	0	3	10
		End	0	6	2	2	10
17	People in the community, or other agencies and organisations, will advocate for and maintain a demand for the existence of the project should it be threatened	Initial	2	2	0	5	9
		Mid	3	5	0	2	10
		End	4	3	1	2	10
18	Community organisations that are similar to the intended host organisation have taken the step of supporting projects somewhat like your project	Initial	0	4	0	6	10
		Mid	1	6	0	3	10
		End	0	4	1	5	10

Capacity building activities documented in the project summaries including building networks (18 projects), enhancing the palliative care capacity of health professionals and care workers (14 projects), training and supporting volunteers (4 projects) and building community awareness of palliative care (4 projects). These activities have been described in detail elsewhere in this report, particularly in the sections on provider and system impacts (Sections 3.2 and 3.3.2). Specific information relevant to capacity building is summarised here.

Project officers used words such as consultation, collaboration and co-operation to describe the processes of building relationships between palliative care providers and other organisations, including the auspice bodies of the projects. Many projects began by creating lists, databases or directories of local services and initiating communication through face-to-face meetings, telephone conversations and email. Networks were maintained via strategies such as regular meetings and newsletters. Some project officers spent time negotiating between groups with conflicting interests. Through this liaison role, projects reported that they were able to encourage groups to work towards common goals including the establishment of a new framework of support for primary care providers from palliative care specialists (TAS-1), a regional 'vision' for palliative care (SA-2) and health services in different regions working together (SA-3).

Capacity building efforts directed at health professionals and care workers had a number of benefits, as described by the project officers. These included changes in rates of referral (VIC-3) and transfer (NSW-7) patterns for palliative care patients, development of expertise with special groups, such as bereaved children (NSW-3, QLD-3) and dementia patients (ACT-3, NSW-6), and active engagement of more than a hundred health workers in helping patients to prepare advance care plans (VIC-5). Training and support activities directed at volunteers also increased general community awareness of palliative care (e.g., NT-1, QLD-5, VIC-2).

Projects operating in rural and remote settings faced particular challenges in building capacity, as demonstrated by a project designed to improve care coordination for palliative care patients in Kalgoorlie (WA-3). The rapid turnover of the local population (30% per annum) presented enormous difficulties, contributing to a high turnover of personnel in the project's advisory committee, the management of the host organisation and among the volunteers. Although the

original project plan involved sending health care providers to Perth for training, it proved more practical to bring in specialists to deliver education locally, spread over several weeks.

In addition to their networking and education activities, many projects conducted extensive research and/or consultation in order to develop new resources. These included protocols for providing workplace support to people with a terminal illness and their carers (VIC-1), protocols for dealing with CALD communities (SA-4), clinical tools (TAS-1, WA-5), a website serving health professionals and the community (VIC-4), a self-directed learning package for community care workers (SA-1), an education series delivered by television to workers in residential aged care facilities in remote areas (NSW-7), a manual and other resources for professionals working with bereaved children and young people (NSW-3, QLD-3), several training manuals and management protocols for volunteers (e.g., NSW-2, QLD-5, VIC-2) and numerous collections of resources for raising community awareness of palliative care, grief, loss and bereavement issues.

Knowledge about palliative care service provision was generated or documented as a main goal or by-product of at least nine projects. Four projects conducted literature reviews, for the following purposes:

- To support the case for a volunteer and bereavement support network (NSW-2)
- To identify the needs of people with end-stage dementia, prior to developing a care model for best-practice palliation (NSW-6)
- To understand the specific effect of culture on the need for bereavement support (SA-4)
- To document existing practices in workplace support for people with life-threatening illnesses and for their carers (VIC-1)

Project evaluations gave rise to a number of interesting findings. For example, one project recommended assessing the need for volunteers prior to recruitment and training as the volunteers had been disappointed when no opportunities were available to demonstrate their skills (NT-1). Nevertheless, the value of including a volunteer service and community development role within local palliative care teams was also demonstrated (VIC-2). A study that attempted to document factors associated with dying at home found that place of death mattered less to carers than their being present at the time of death, wherever the patient was (NSW-8). Another project demonstrated that the quality of end-of-life care could be enhanced through the routine use of advance care planning. Most people do not want the dying phase of their lives extended, and wishes that have been documented are generally respected (VIC-5). The interest generated by another project led to the writing of a position paper on dementia and palliative care by Alzheimer's Australia (ACT-3).

One issue arising from discussions at the second national workshop was the capacity built within the group of project officers who worked on the 37 CCP projects. Many of these people were employed on short-term contracts and have since moved on to new positions. Due to the fragmented nature of project work, there is a strong possibility that much of the capacity generated during CCP could be lost. It was suggested at the workshop that it would be advantageous to retain their skills, knowledge and experience in the palliative care sector somehow, possibly by establishing a register of project workers.

3.6 Generalisability

Respondents were very positive, both about the projects' applicability in their own contexts and the prospects for transferring some aspects of the projects to other settings (see Table 4). Responses were very stable over time, with little change between the outset and midpoint of projects. This suggests that generalisability is a characteristic of a project that is built into its design and can be judged reasonably accurately at the commencement of project work.

About half of the project officers who completed the checklist at all three time points said their project was designed to meet local needs (Q1). All stated that the project was designed to develop capacity in palliative care in their own region, service or organisation (Q5) and most claimed that its success would depend on how sensitive and appropriate it was to the target population (Q4). Nevertheless, all also believed that other regions, services or organisations could learn useful lessons from the project (Q2), and that it was reasonable to expect that outcomes could be replicated elsewhere (Q3). Most agreed fully with the statement that the project was designed to enable people not directly involved in it to develop skills and/or knowledge in palliative care (Q6). In the whole data set there was somewhat greater confidence at the first time point that the work of the projects could be generalised to other settings (Q2, Q3). It appears that some project officers who were initially very confident about generalisability did not submit the checklist at later time points.

By the end of the CCP, all respondents at least partially agreed that they had a strategy in place for sharing their findings and experiences (Q7, Q8).

Table 4 Responses to Generalisabiity Tool at project commencement (initial), midpoint and end (excludes projects with data at less than three time points)

No	Item	Timing	Yes, fully	Yes, partly	No	Don't know	N
1	Our project is designed specifically to meet our own local needs	Initial	4	4	3	0	11
		Mid	5	3	3	0	11
		End	5	5	1	0	11
2	Other regions/services/organisations will learn useful lessons/information from our project	Initial	6	4	0	1	11
		Mid	10	1	0	0	11
		End	10	1	0	0	11
3	It is reasonable to expect that the outcomes of our project could be replicated elsewhere	Initial	8	3	0	0	11
		Mid	11	0	0	0	11
		End	11	0	0	0	11
4	Our project will depend on how sensitive and appropriate it is to our target population	Initial	8	2	0	0	11
		Mid	6	4	1	0	11
		End	8	2	1	0	11
5	Our project is designed to develop capacity (skills and/or knowledge) in palliative care in our region/service/organisation	Initial	9	2	0	0	11
		Mid	10	1	0	0	11
		End	11	0	0	0	11
6	Our project is designed to enable people not directly involved in our project to develop capacity (skills and/or knowledge) in palliative care	Initial	9	2	0	0	11
		Mid	9	2	0	0	11
		End	9	2	0	0	11
7	We already have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care	Initial	3	7	0	1	11
		Mid	6	5	0	0	11
		End	7	4	0	0	11
8	By the time the project ends, we will have a strategy in place to ensure that our experience and findings are shared with other people who want to develop and improve palliative care	Initial	7	4	0	0	11
		Mid	9	2	0	0	11
		End	7	4	0	0	11

According to the project summaries, most of the projects that developed resources or models of service delivery have asserted that these could be used widely. Their actual applicability in other settings would have to be assessed on a case-by-case basis by organisations wishing to use

them. The extent to which CCP resources are generalised will depend to a large extent on whether they are well publicised and accessible. Some projects have taken steps to ensure their resources are easily accessible to other potential users (e.g., NSW-5, SA-2).

A few projects have demonstrated that their resources are generalisable:

- A self-directed learning package for community care workers was tested nationally (SA-1).
- A best-practice model for managing palliative care volunteers has been adopted by other organisations in their applications for new services, while the associated resources (evaluation tools and documentation, policies and procedures, training materials and a volunteer handbook) update an earlier, 'classic' reference work (QLD-5).
- The website developed for Palliative Care Victoria provides information and links from across Australia and could be developed further into a national palliative care resource, while the methods of developing the website were well documented and could be used for similar evidence-based online resources for other community organisations (VIC-4).
- Satellite television was shown to be a cost-effective and efficient training method for residential aged care workers at a cost of approximately $50 per staff member. Provided the education component is designed thoughtfully, satellite television could be used to provide training in other health care settings (NSW-7).
- Protocols for working with Aboriginal and CALD communities developed by another CCP project have been adopted by mainstream health providers working with patients and families from these groups. This information has also been included in the SA Companion Book of the *Providing culturally appropriate palliative care for Indigenous Australians* resource kit (SA-4).

Models and practices developed by CCP projects include methods of community engagement, volunteer training and support, carer education and support, and care coordination. Again, relatively few projects have provided evidence that these are generalisable. Examples of models that could be used more widely include:

- A service delivery model which provides a framework for primary care and specialist palliative care providers to work together. This model has been endorsed by key stakeholders and will be implemented across Tasmania (TAS-1).
- A team of professionals and volunteers were trained in health-promoting palliative care and then applied their knowledge to invite and assess applications from community groups for small grants. These seed funds were used for a variety of awareness raising activities in the local area. Evaluation of these activities enables the region to gather evidence on the effectiveness of strategies, to help make future submissions for sponsorship (VIC-2).
- Clinical attachments for general practitioners worked well because the project provided strong organisational support, paid time away from practices, reduced paperwork involved in claiming CPD points and some tailoring of the content to be relevant to participants' caseloads (VIC-3).
- Training in advance care planning was originally targeted to people working with palliative care patients and residents of aged care facilities, but was successfully extended to cater for frail aged people living in the community (VIC-5).
- An outreach education project in rural and remote areas successfully engaged general practitioners as well as a variety of other health care providers and had excellent learning and clinical outcomes. The model could be transferred to other areas of health that require a multi-disciplinary approach (QLD-1).
- Independent external evaluators recommended that a model of bereavement work with children, which has been developed and refined through the work of a CCP project, should be widely disseminated (QLD-3).

- Many features of one CCP project – multi-disciplinary teams that meet regularly, with good support from GPs – were similar to work done in other rural towns, demonstrating that this approach is suitable for communities of a comparable size (WA-3).

3.6.1 Discussion: Sustainability, Capacity Building and Generalisability

The checklist tools provide some interesting insights into the ways in which CCP projects have built capacity and ensured sustainability and the prospects for applying the lessons learned more widely. Although the declining response rate (and correspondence with the NET) shows that completing these tools could be a time-consuming task for some project officers, others did comment that the process of formulating and documenting their strategies was a useful one (see Section 4.2.6 for more details on the project evaluation processes).

The pattern of complete versus incomplete data from the CCP projects is suggestive. For many questions, responses from projects that did not submit complete data tended to be more positive (that is, there were more 'yes, fully' answers and fewer 'no' and 'don't know' answers) than responses from projects that completed checklists at the beginning, middle and end. This suggests that projects submitting early checklist data but not late were less successful than anticipated, while those who submitted data later but not earlier did so because they had good results to report. However, although statistical techniques are available to assess changes over time in longitudinal, ordinal data, we chose not to do so because of the small number of projects that provided complete data for all three time points. Therefore, the discussion of changes over time and of differences between complete and incomplete data should be treated with caution.

Within the tools, some questions showed a more coherent pattern of responses than others. The validation of these tools against data from this and other palliative care projects is potentially a task for future research.

The qualitative data also document some successes in sustainability, capacity building and generalisability. These include continuing staff roles, the use of evaluation findings to obtain additional funding, strategies for the maintenance of provider and community networks and the dissemination of the resources and models developed by projects.

3.7 Dissemination

An important outcome of the National Reference Group was the need to encourage projects to share their goals/activities with others. This led to the inclusion in the final evaluation framework of a key question 'Dissemination – who did you tell?'. In order to assist projects to collect these data, a dissemination tool (Tool 7) was included in the toolkit. Also, in order to meet specific reporting requirements, this tool was incorporated into the template for the six monthly project reports to the DoHA. This allows the data to be captured throughout the CCP, ensuring more accurate recording of these impacts, which may otherwise be forgotten if Projects are only required to report on them at the conclusion of their Project.

The six monthly reports have revealed that, over the life of the CCP, project officers have been very active in disseminating information about their goals and activities to health care professionals, stakeholders and the general community. This has been facilitated through many different mediums including:

- Presentations or talks to staff at one service or agency in the local area
- Talks to staff from more than one service or agency in the local area
- Stories in local newspapers
- Stories or articles in local magazines or newsletters
- Stories or articles in professional or industry magazines or newsletters

- Information provided on websites
- Interviews on local/national radio
- Stories on local/national television

With regards to disseminating information to an academic/professional audience up until the September 2005 reporting period several projects had presented posters or papers at conferences as follows:

- Six papers or posters at a local conference
- 17 papers or posters at a State/Territory conference
- 19 papers or posters at a national conference

In part this conference activity was supported by the DoHA who provided funding of up to $5,000 per State and Territory to support activities such as attendances at conferences.

Also over the life of the CCP several peer reviewed journal articles have been accepted for publication.

4 The strategies and processes of the Caring Communities Program

The focus of this section is on the nature of the CCP and how it was delivered. Processes at the level of the overall program and within individual projects are described. The results presented here are based on the findings from various evaluation activities such as a review of (DoHA) documents from the central management of the CCP, interviews with project officers and other stakeholders, the use of the evaluation toolkit and the initial and final examination of project plans and reports

4.1 Program-level strategies and processes

This section describes the institutional arrangements for the CCP and, where possible, their impacts on program outcomes. These include the roles of the DoHA, State Health departments, the NET and Palliative Care Australia. Information presented here is based on a review of the program documentation, interviews with key stakeholders at three time points (commencement, midpoint and end) of the program, exit interviews with project officers and project summaries. As the NET did not have access to Central Office DoHA files information relating to program design, selection and management strategies was complied by DoHA officers into a document entitled 'The Development and Implementation of the CCP'. The following information draws on this document.

4.1.1 Program planning and project selection

The National Palliative Care Program grew out of a concept referred to as the Community Capacity Building program. This was a community-focused initiative aimed at improving the quality of palliative care. This was to be facilitated by promoting strong partnerships between all levels of government, the community, individuals and business to facilitate access to a comprehensive range of services.

Representatives from PCA, the Cancer Council, the National Rural Health Alliance and the Australian Divisions of General Practice held a workshop in March 2003 to develop the idea of a community capacity building program. The workshop decided upon a themed approach to the types of projects that could be funded under this initiative. These themes were identified as:

- Projects that address isolation;
- Community awareness projects;
- Education programs for those involved with the dying;
- Promoting and strengthening existing community and professional networks and linkages; and
- Phone and web based information services.

Following the budget announcement in May 2002 officers of the DoHA felt that it was important to disperse the money amongst relevant community organisations as soon as possible and to focus on a national program that builds capacity at the local community level. It was also recognised that there would have to be a sufficient lag time between calls for expression of interest and receipt of final submissions in order to allow for the fostering of community partnerships.

DoHA staff also recognised that an effective model for program implementation would have to be developed. With this in mind a model from the South Australian State Office was adopted to assist with the early developmental phases of the program. To help support this process the 2002 budget provided funding for staff resources at both central and state/territory level and in June 2002 State Managers were asked to nominate staff members to work on the CCP as part of the NPCP.

Following from the positive experiences of the National Suicide Prevention Strategy (NSPS) it was decided to give each State and Territory autonomy to manage the CCP in each jurisdiction. The DoHA felt that this would produce more local 'ownership' of the program and increase the level of engagement with key stakeholders. Other important lessons form the NSPS that were adopted by the CCP included:

- asking for expressions of interest before a full application is provided;
- better communication and updates on national projects;
- consideration of timelines and critical deadlines for different programs;
- including state offices in, or at least advising them of, any meetings in their jurisdictions; and
- developing an evaluation plan from the outset.

4.1.2 Governance and Expert Advice

Several bodies were established or involved to oversee the development and implementation of the CCP. This included:

- a National Reference Group (NRG)
- the Palliative Care Intergovernmental Forum (PCIF)
- Expert Evaluation Advisory Group (EEAG)
- Palliative Care Australia (PCA)

4.1.2.1 National Reference Group (NRG)

The NRG was established in June 2002 to oversee the overall direction of the CCP, including the selection process. The NRG was managed by, and reported to, the DoHA. Membership of the NRG included representatives from the DoHA's central and state/territory offices, state governments, PCA, the Cancer Council Australia, Carers Australia, the Council on the Ageing, the Australian Divisions of General Practice, the Australian Rotary Health Research Fund, the Australian and New Zealand Society for Palliative Medicine, the DoHA's National Strategies Support Working Group and a spiritual advisor.

Broadly the NRGs terms of reference were to provide appropriate guidance and support for the project by ensuring the needs of their sectors are being addressed and to provide expert advice as needed.

Three meetings were held in November 2002 and February and July 2003. In January 2004, following discussion with its members, it was agreed to disband the NRG. In making this decision, it was recognised that the NRG had very effectively fulfilled its role during the previous 18 months. It was felt that further meetings of the NRG would not be required with the successful implementation of the CCP and its supporting infrastructure.

It was requested that the DoHA (in conjunction with NET) distribute updates on the CCP and its evaluation. In accordance with this, the NET distributed a second and final report to members of the NRG in February 2004.

4.1.2.2 Palliative Care Intergovernmental Forum (PCIF)

The PCIF is made up of representatives from the DoHA and State and Territory health departments. PCIF members were involved in the selection of CCP projects within their jurisdictions and were represented on the NRG.

4.1.2.3 Expert Evaluation Advisory Group (EEAG)

The EEAG was formed to oversee the evaluation process and to provide logistic support, advice and direction as required to the national evaluator. The terms of reference for this group focused on communicating with the national evaluator as required and offering assistance, guidance and feedback with evaluation methodology.

On 2 July 2003, Professor Kathy Eagar participated in a teleconference with the EEAG to discuss and approve the evaluation framework. At this meeting, the EEAG resolved to disband, considering that it had completed its task following the appointment of the CHSD as the national evaluator of the CCP. Since that time EEAG members have been kept updated of important developments relating to the CCP through the CCP group email list.

4.1.2.4 Palliative Care Australia

PCA was funded for a period of nine months from August 2002 to provide support services for the CCP. This included overall administrative support for the CCP, secretariat support to the NRG, promotional activities and the management of the selection and assessment process.

4.1.3 Program Management by the Department

The DoHA created a guide about the CCP for project officers in State and Territory offices. This document set out the roles and responsibilities of the Palliative Care Section, Rural Health and Palliative Care Branch and the State and Territory offices in relation to the administration of the CCP. With regards to the State and Territory offices the guide was disseminated in an effort to ensure a consistent approach to administer funds and projects under the CCP.

4.1.3.1 Funding

The amount of funding provided for the CCP was revised upwards to a figure not expected to exceed $5m between the 2002/03 and 2005/06 financial years. This was divided into $4m for grants and $1m for associated activity such as communication, workshops, the reference group, evaluation and secretariat functions.

State and Territory funding was made available according to the Australian Health Care Agreement's (AHCA) formula. In accordance with this states and territories received a baseline funding amount of $50,000 per $1m received and the remaining $600,000 was distributed using the AHCA formula.

Using this formula states and territories received the following levels of funding to set up the CCP in their jurisdiction:

- New South Wales - $1,011,200
- Victoria - $722,000
- Queensland - $632,000
- Western Australia - $420,800
- South Australia - $396,800
- Tasmania - $260,000
- Northern Territory - $250,400
- Australian Capital Territory - $236,000

4.1.3.2 Application process

In conjunction with the DoHA, PCA put together selection documentation together with application forms and application guidelines. This documentation was distributed to all states and territories offering funding of between $50,000 and $200,000 to organisations to improve the quality of palliative care in the community. The documents, in acknowledgment to the complexity of palliative care issues, identified a wide range of initiatives addressing several themes associated with palliative care including:

- Improving community awareness of palliative care
- Supporting dying people and their families
- Increasing awareness of palliative care as an integral part of the health care system
- Delivering education to support professionals who are delivering palliative care services
- Creating effective partnerships between palliative care providers, other health service providers and health systems, to coordinate care for dying people

PCA advertised the CCP on their website and set up a dedicated 1800 telephone number through which interested organisations could access documentation and receive assistance with completing their applications.

The CCP was also advertised nationally in the newspaper on 5 October 2002 with a closing date for applications of 29 November 2002. The CCP raised much enthusiasm in community palliative care with 277 applications received totalling $41million.

4.1.3.3 Selection and Assessment Process

State and Territory departmental offices were responsible for establishing a selection panel in their jurisdiction to assess the CCP applications. Guidelines suggested that each selection panel should consist of at least:

- State/Territory departmental officer, who would chair the panel and organise meetings;
- PCIF representative; and
- Community representative with palliative care expertise.

States and Territories were guided by the principles of the selection criteria in the guidelines developed by PCA and a suggested selection proforma and guide was provided to State and Territory offices by central office to assist them in this process.

The following information is taken from key stakeholder interviews in each state and identifies how the selection process was managed in each jurisdiction. Interestingly, despite rigid guidelines being disseminated from central office, the selection process was subtly different in each jurisdiction.

ACT – the selection panel consisted of representatives from both the local DoHA and State Health offices, a health care consumer representative and a member of the local Palliative Care Partnership Team (PCPT). Prior to submitting their proposals interested agencies in the ACT contacted the PCPT to discuss their proposal. This was used by the PCPT as a quasi-filtering process for applications. At the closing date the ACT had received five applications for funding under the CCP.

The feeling by the members of the ACT selection panel was that with a limited budget for the CCP in their area ($236,000) they would try and ensure that they got value for money. The key decision was how many projects to fund i.e. two or three with a significant level of funding or many projects with less funding. Ultimately, projects were culled on the basis of how their goals and aims

concurred with the key objectives of the CCP. This resulted in the unanimous selection of three successful applications. Two of the successful applicants were also members of the PCPT but the selection panel was careful to avoid a conflict of interest. Although the decision by the selection panel was unanimous they decided to increase the capacity of the ACT Carer's project by $15,000 and reduce the bid from ACT Hospice by the same amount.

Tasmania – the selection panel consisted of a consumer representative, a representative from DoHA and a State health representative. Twelve applications were received from a wide range of stakeholders including the private sector, acute care, carers, the aged care sector and respite services. These applications were culled using the selection criteria provided by PCA and ultimately two projects were successful. A conflict of interest occurred as a member of the selection panel had a significant role in putting one of the successful bids together. However this member left the room when that project was being discussed. Ultimately two projects were selected in Tasmania.

South Australia – the selection panel consisted of a local palliative care expert, a representative from SA State Health Department and a representative from the local Commonwealth office. Again the selection criteria set up by PCA were used to cull applications. The selection panel tried to ensure that the successful applicants represented a good mix of metropolitan and rural SA, were a good mix of constructs to avoid duplication of services and were represented by an organisation with the capacity to deliver the project's goals and aims. The selection panel also placed importance on the provision of a needs assessment and on applications that had a broad application of their outcomes. In some cases clarification was sought from applicants. Ultimately four projects were selected in SA.

Queensland – a total of 66 applications were received of a very high standard. The sheer volume of applications received in Queensland was burdensome for the selection panel and they felt that there was not enough time available to do justice to the task. In the words of the State Queensland Health representative, the selection process felt like a 'mad rush'.

The main objective of the selection panel was that the successful projects should aim to improve palliative care outcomes for clients and carers and not just be a 'flag-waving' exercise for DoHA. It was also felt that since the service delivery and capital implications had to be met by the state in the long run it was important that the projects did not duplicate existing services or leave big expectation gaps at the wind-down phase.

The selection panel in Queensland felt that there was little understanding for the context of service delivery, especially about what was in place in the state already. With this in mind some sort of population-based criteria or needs assessment relating to palliative care would also have been helpful in assisting them in their task. They also felt that they would have benefited from evidence from other related programs for similar target groups.

In the absence of this 'big picture' information the good applications were based more on the applicants' areas of interest rather than filling the gaps in service delivery. Therefore, the selection panel felt that a more strategic approach would have been to agree on more basic criteria such as big or small agency types, urban, rural or remote, potential for networking and mentoring, or to balance the types of services promoted by the projects – volunteer training, care planning, GP EPC assessment roles, community services culture change, general community awareness, support for small communities in remote and rural settings.

New South Wales – seven selection panel members representing local key stakeholders went through over 100 applications. In view of the sheer number of applications they were divided up amongst the members of the selection panel equally. Panel members felt that the selection criteria were too broad which meant that most of the applications met the criteria. Those applications rejected using the PCA guidelines were not discussed further by the panel. However,

the applications that made it through this culling process were discussed by the entire team. In the instances where a panel member had an application submitted they were not part of the discussion and they left the room.

A short list of projects was then sent to the Commonwealth for their final selection. As part of the culling process consideration was given to projects with a good mix of objectives and approaches. A balance of rural and remote and metropolitan was also a desirable as were organisations that had not received similar funding before.

The final list then went to central office and a final cull was made with support from a representative with palliative care expertise from the NSW State Government. Central office discussed some of the projects on the list to clarify why they were on the list. The projects were selected based on the strength of the application. They needed to have a minimal level of skill to complete the form and this was a factor in being selected (that is, they needed to have written a coherent application). It was particularly advantageous to have somebody involved on the selection panel with a good knowledge of palliative care service delivery in NSW as this avoided the possibility of funding projects that would duplicate existing initiatives or resources.

Northern Territory – The selection panel included representation from Territory Health Services, Palliative Care Australia and Hospice (Alice Springs) and an Aboriginal and Torres Strait Islander consumer representative. Eleven applications were received of which four were outside the guidelines and there was one cross-jurisdictional project that was handed back to the Australian Government. This left six projects to choose from. A list of possible selection criteria were then devised and a process was agreed upon to shortlist the applications. An attempt was also made by the selection panel to agree on what they felt the NT community palliative care priorities were. It was also felt important to try and get a good regional mix of projects in the Centre and the Top End.

The selection process was undertaken very quickly. Applications closed on 29 November 2003 and the projects had to be signed off by 13 December 2003. It was felt locally that if more time was allowed for the application and decision making process that there may have been different results in terms of who got funded. It was felt with hindsight that there were other organisations that could have applied for funding which could have done a ‘better job’. However, there was not enough time for these organisations to produce a viable proposal.

There were negotiations about funding levels in the Territory that from the outset was considered obstructive to progress. Again in hindsight, it may have been better to not fund particular projects, rather than changing projects to suit the funding that was available. It was felt by the selection panel that due to the limited funding available in the Territory you really could only have very limited expectations from the outcomes of the successful projects.

Western Australia – The selection process was well managed in Western Australia due to the level of expertise of the selection panel. The panel included representatives from the manager of palliative care program in the state office, a palliative care expert from Edith Cowan University, a GP representing the local Division of General Practice, an Aboriginal and Torres Strait Islander community representative and two representatives from DoHA.

Approximately 20 applications were received and panel members reviewed each of the applications prior to the selection panel meeting. The culling process was straightforward and the process was fair and equitable. The state government representative was particularly helpful and had a good knowledge of existing palliative care services in the state. This ensured that there was no duplication of resources and where relevant successful CCP projects in Western Australia added value to existing state processes.

Victoria – The selection panel consisted of a representative from Palliative Care Victoria, the manager of palliative care and specialist programs from the Victorian Government Department of

Human Services and a DoHA representative from the Victorian office. Victoria received 78 submissions and panel members assessed each individually before meeting collectively to cull them to a short list of 12 applications. Culling was made easier by the fact that many of the applications were very specific and did not fit with the broad objectives of the CCP. More specifically, panel members looked for applications that were innovative, potentially generalisable to other settings and of general relevance to palliative care in Victoria. Ultimately, five projects were funded in Victoria.

The decisions of the selection panels in each State and Territory were included in a report to central office outlining reasons for selection and non-selection. The departmental delegate then went through these reports and thirty seven projects were approved for funding nationally. This final 'central' selection process was crucial and ensured that the recommended short-listed projects did not duplicate existing resources in each state and nationally and were consistent with departmental policies. Based on this selection process thirty seven successful applicants were notified on 31 March 2003.

Due to the level of response and the quality of the applications additional funding ($715,280) was allocated to most States and Territories to increase capacity.

One of these successful projects in NSW (Home Hospice NSW) withdrew from the CCP without entering into a contract as they could not agree on the deliverables. A replacement project was selected from Queanbeyan, NSW.

The overall feeling about the selection process from the perspective of the State and Territory offices was that it was sometimes difficult to engage palliative care experts due to potential conflicts of interest. It was also agreed in many cases that the selection criteria were too broad meaning that there were so many different types of initiatives that could potentially be funded. Perhaps a more targeted approach would have been preferred. It was also felt that the timelines for making an application and selecting projects was very tight, possibly limiting the quality of applications and placing undue pressure on the selection process.

Specific feedback from a couple of jurisdictions highlighted the funding divide between regional/rural projects and metropolitan projects. It was felt that metropolitan sites were funded more generously than their rural/regional counterparts.

4.1.4 Review of project plans and evaluability assessment

The initial site visit to each project included an evaluability assessment. This involved examining and discussing project plans to determine if the projects were able to be evaluated and, if not, what modifications or assistance were necessary. A checklist was used to guide each visit and summary complied on each project. Most of the initial site visits were carried out from June-September 2003. Some of the site visits were conducted jointly with the DoHA state officers. The DoHA state officers reported that these joint visits were beneficial in assisting them to gain an understanding of the evaluation issues. The joint visits were also an opportunity to clarify the roles of the DoHA state officers and NET with the project teams.

Project plans had not been completed in many of the early visits, and the project schedule was used as the basis for discussion. Other project plans were rich in detail but very difficult to understand. This meant that considerable amounts of time were put into the interpretation of project plans before any assessment could be made of whether the project was able to be evaluated or not.

Most of the project plans were very detailed in terms of the activities that would be performed but, in some cases, less attention was paid to how the effectiveness of these activities could be monitored and reported. The need to evaluate activities was not completely understood by some of the projects, especially those that were continuing an existing service. Some project officers felt that the evaluation took time away from those activities that were of local importance.

The level of evaluation activities built into the project plans depended on the experience of the project leaders and their partner organisations. Some projects employed external evaluators, had clearly defined evaluation activities and had identified appropriate evaluation tools. More typically, however, it was necessary for the NET member to work through the project plans (or whatever documentation was available) and suggest where evaluation activities could take place and recommend tools that projects could utilise. This included explaining the evaluation framework and CCP toolkit and if appropriate, selecting tools. Table 5 summaries the results of the evaluability assessments completed at the end of each initial site visit.

Prior to the first national workshop, the NET reviewed the successful applications for CCP funding and estimated that 18 of the projects had local evaluation expertise in place while 19 did not. The results of the evaluability assessment (Table 5) suggest that the initial estimate was reasonably accurate.

Table 5 Evaluability Assessment Summary

Summary Availability Assessment	Total
External evaluator employed, project is capable of being evaluated	6
Well developed evaluation plan requiring little further assistance	15
Requires assistance to develop evaluation activities and ensure that project can be evaluated	16
Total	**37**

As part of the initial site visit, an assessment was made by the NET of the ongoing support needs of each individual project. This assessment was based on the unique conditions and the varying levels of experience of each project. In accordance to this assessment, the NET gave each project varying levels of support, by way of site visits and telephone communication.

All projects were assessed for risk of being unable to maintain their commitment to the CCP, especially the evaluation activities, during every reporting period. This was performed by the NET by reviewing the project six-monthly progress reports and then agreed on by the DOHA state officers. If a project was deemed 'at risk' additional site visits and regular telephone communication were conducted.

It was necessary to conduct additional site visits to projects that were considered to be at risk. Three projects received such additional visits. Following the site visits, one project was considered no longer at risk, but the other two remained at high risk.

This role of ongoing support and advice proved extremely important to the CCP. There were many changes that occurred during the life of the projects and program. For example, changes occurred as a result of recruitment issues e.g. project officers leaving; or when there were changes in other parts of the system e.g. area health amalgamations; and when parts of the project was working or not working e.g. modifying the project plan. All these changes could have effects on the evaluation process. By reviewing the six-monthly project plans, the NET was able to capture any new or changing issues. Any key issues would be discussed with the DoHA state officers and/or projects.

4.1.5 Evaluation tool kit

The need for an evaluation tool kit was initially discussed at the first national CCP workshop held in Canberra in May 2003. At this meeting it became clear that many of the CCP projects required measurement/evaluation tools, but were unsure of what tools to use and where to obtain them.

After reviewing the requirements of each project the NET set about compiling a range of tools for the projects to use. To meet this need, an extensive literature review was conducted to determine the availability of tools for palliative care assessment and the relevance of these tools for the

context of the CCP. In some cases, individual projects had already developed tools that they were willing to share with other projects. An example of this is the tools for remote Aboriginal communities, which were developed by the Kimberley Regional Aboriginal Palliative Care Coordinator, and shared with many of the other Aboriginal and Torres Strait Islander projects. Finally, in some cases it was necessary to develop new tools. In these cases, the tools had to piloted, where possible, to determine the validity of the concepts they included with appropriate population groups.

The resulting tool kit[2] covers the three levels of the evaluation hierarchy as described in the evaluation framework. There are tools at the level of the consumer, family and community, at the level of service providers and at the level of the system. The projects were not obliged to use the tools in the tool kit. However, projects were encouraged to use the tools, rather than attempt to develop new ones. In doing this it was hoped that projects would collect common data that could be comparable between projects. It was hoped that this approach would assist the CCP as a whole to achieve a better picture of the generalisability of the findings of individual projects to the wider field of the palliative care community. With this in mind the NET developed an Access database to facilitate tool kit data entry. This database was distributed to the CCP projects and is available on the CCP website (http://www.uow.edu.au/commerce/chsd/palliative_care.html) for general usage.

The Tool Kit was mailed to each of the sites in December 2003 and will continue to be available at the CHSD website (http://www.uow.edu.au/commerce/chsd/palliative_care.html). Early feedback from the projects encouragingly suggested that approximately 25 out of the 36 projects would use at least one of the tools in the toolkit. However, it became apparent as the projects established themselves that this initial estimate was optimistic with only 13 of the 37 projects using at least one of the tools in the Tool Kit. Use of the tools is reported in Table 6.

Table 6 Use of tools from the CCP evaluation tool kit

No	Tool	Project
1. Impact on and outcomes for consumers (patients, families, carers, friends, communities)		
1.1	Patient / client palliative care stage of illness data set	Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities
1.2	Patient /client experiences – patient questionnaire	-
1.3	Patient /client experiences – staff-completed questionnaire	-
1.4	Carer experiences with palliative care	Helping Communities Care (Orange, NSW)
1.5	Community Awareness of Palliative Care	Palliative care - empowering the Southern Midlands community through information and integration – Tasmania Bundaberg Palliative Access Link (PAL) Project Building rural community capacity through volunteering Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities Kangaroo Island palliative care project Helping Communities Care (Orange, NSW)
1.6	Community Awareness: Remote Aboriginal and Torres Strait Islander Communities	Greater Darwin Palliative Care Volunteer Support Project – NT Groote Palliative Care Support Service - NT Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities - WA Fitzroy Valley Palliative Care Service – WA

[2] Eagar K, Senior K, Fildes D, Quinsey K, Owen A, Yeatman H, Gordon R and Posner N (2003) *The Caring Communities: Evaluation Tool Kit: A compendium of tools to aid in the evaluation of palliative care projects*. Centre for Health Service Development, University of Wollongong http://www.uow.edu.au/commerce/chsd/palliative_care.html

No	Tool	Project
2. Impact on, and outcomes for providers (professionals and volunteers)		
2.1	Palliative Care providers	Palliative care - empowering the Southern Midlands community through information and integration – Tasmania Shared Understandings Improving Palliative Care for People with Dementia Kangaroo Island palliative care project
2.2	Volunteers currently working in palliative care	Greater Darwin Palliative Care Volunteer Support Project - NT Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities Volunteer Palliative Care Support Network Initiative Helping Communities Care (Orange, NSW)
2.3	New Palliative Care Volunteers	Greater Darwin Palliative Care Volunteer Support Project – NT Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities Kangaroo Island palliative care project Volunteer Palliative Care Support Network Initiative
2.4	People ending their time as a Palliative Care Volunteer	Greater Darwin Palliative Care Volunteer Support Project – NT Volunteer Palliative Care Support Network Initiative
2.5	Health Professionals Not Working in Palliative Care Services	Palliative care - empowering the Southern Midlands community through information and integration – Tasmania Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities Helping Communities Care (Orange, NSW)
2.6	Health Workers in Remote Aboriginal Communities	Greater Darwin Palliative Care Volunteer Support Project – NT Groote Palliative Care Support Service – NT Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities - WA Fitzroy Valley Palliative Care Service – WA
3. Impacts on the system (structure and processes, networks, relationships)		
3.1	Palliative Care Service Self-Assessment	Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities Kangaroo Island palliative care project
3.2	General health care organisational survey	Kangaroo Island palliative care project Helping Communities Care (Orange, NSW)
4	Sustainability Tool	All projects
5	Capacity Building Tool	All projects
6	Generalisability Tool	All projects
7	Dissemination Log	All projects
8	System level impacts and outcomes of the Caring Communities Project	Building rural community capacity through volunteering

This limited use of the tools meant that few of the projects collected common data that made it inappropriate to group and analyse the data collectively. However, many of the CCP projects indicated that they found the toolkit useful and were able to modify specific tools to meet their own requirements.

This limited use of the tools in the kit could be for many reasons. Some of these reasons may come from the following:

- Timing – the CCP Toolkit was released in December 2003 and many of the projects that commenced in early 2003 had already developed their own evaluation tools and had started to collect data.
- 6 of the projects were evaluated externally and used tools developed in partnership with the evaluator.
- Many of the tools were too general and not specific enough for the unique requirements of some of the CCP projects e.g. Motor Neurone Disease.
- In some cases ethics applications were already underway for some of the projects committing them to use their own evaluation tools.

Three of the tools in the kit were compulsory: Tool 4 – Sustainability Checklist; Tool 5 – Capacity Building Checklist and Tool 6 – Generalisability Checklist. These tools were developed and refined prior to inclusion in the Toolkit and were designed to contribute to the overall program evaluation and to reflect key issues identified in the original tender submission on 'Evaluation hierarchy'. These three tools provide a systematic approach to considering these broader issues of the contribution of the projects to Palliative Care. Some project officers struggled with the terminology used in tools but agreed that it was important to keep the issues of generalisability, capacity building and sustainability on the agenda and to try and address these issues. In this way the tools were used more as a planning tool rather than an evaluation tool by project officers. The results from use of the tools are presented in Section 3.4.

A fourth tool, the Dissemination Log, was also included as a compulsory tool in the Tool Kit (see Section 3.7).

4.1.6 Communication and support strategies

Various activities to help promote communication have been implemented by the NET. They include the CCP Discussion Page, the CCP Evaluation Hotline, the CCP Website, several CCP Evaluation Bulletins, two CCP national workshops and NET site visits to each of the CCP sites. These are discussed in more detail below:

4.1.6.1 Discussion page

One of the deliverables for the project was that the NET develop a regularly convened internet 'chat room' service that would enable CCP projects to communicate amongst themselves and share their ideas and knowledge. Prior to establishing this, the NET further explored this idea with project officers at the inaugural site visits. The feedback from these visits suggested that the chat room was too limiting in that having to be available at a specific time in front of a computer was unrealistic for some project officers. Additionally, a number of the projects were not familiar with using a chat room and did not feel confident in accessing the system.

This feedback meant that a new approach was required and it was decided to explore the possibilities of setting up a CCP Discussion Page to facilitate communication. It was believed that a discussion page would be more user-friendly and accessible than a 'chat room'.

The NET raised this issue at the CCP National Reference Group Meeting on 30 July 2003. This idea was further developed at a State and Territory Officers teleconference on 1 August 2003 facilitated by the Commonwealth. This meeting suggested that the theme of the discussion page could be broadened to include a wide range of questions about the CCP in general rather that just being focused on the evaluation.

On 24 September 2003, after further consultation with the Commonwealth, this discussion page was launched. The purpose of this discussion page was to provide a password-protected area for

everyone involved in the CCP to exchange ideas and benefit from the broad range of knowledge and experience within the palliative care community.

The discussion page included the following features:

- Password protected access
- Search engine
- Contents page documenting all submissions to the discussion in chronological order
- Counter facility which calculated how many users have viewed the pages

Unfortunately, the discussion page never quite lived up to expectations. Despite the fact that forty five people registered for a password in order to access and interact with the discussion only eight entries were made (four of these coming from the NET) in almost three years.

Feedback from one of the CCP projects suggested that the discussion page may have worked better if it was more thematically oriented and more information driven. The NET also believe that, on reflection, the development of an email 'group' would have been a more relevant tool to share information since people are more likely to access their email than log onto a web page. This approach has certainly been more successful in the Rural Palliative Care Program.

4.1.6.2 CCP Evaluation Hotline

The establishment of a 24 hour telephone hotline service was another deliverable to facilitate communication between the CCP projects and the NET. The purpose was to allow CCP project officers to ask questions about evaluation issues or to seek assistance or support. It was hoped that this would enable the NET to provide targeted assistance as required. The hotline was established in March 2003 and the telephone number was advertised in Evaluation Bulletin, Number 1, April 2003.

Unfortunately the hotline was under-utilised and only received three calls throughout the life of the CCP. There are two possible explanations for this:

- Project officers prefer to liaise directly with their individual NET member rather than get referred on the hotline; and/or
- Calls are not really 'hot-line' type issues that require instant attention and feedback.

4.1.6.3 CCP Website

The CCP Website (http://www.uow.edu.au/commerce/chsd/caring_communities.html) was launched in July 2003 and has had a significant amount of interest in terms of 'hits'. The Caring Communities webpage includes many useful resources including the CCP evaluation bulletins, the CCP evaluation tool kit, the CCP discussion page, a one-page summary of CCP and a link to the highly informative CareSearch webpage following permission from the Flinders University Department of Palliative and Supportive Services.

In addition to this a separate palliative care research page was created in August 2004 (http://www.uow.edu.au/commerce/chsd/palliative_care.html). This page included resources relevant to the CCP projects such as a guide to ethical research in palliative care, another guide relating to the specific issues relating to evaluating palliative care projects and the palliative care evaluation toolkit.

Between July 2003 and July 2006, these sites and their associated links received 67,352 'hits'. A monthly breakdown of these 'hits' is shown in Figure 1.

Figure 1 Total number of monthly 'hits' to the CCP and Palliative Care web pages

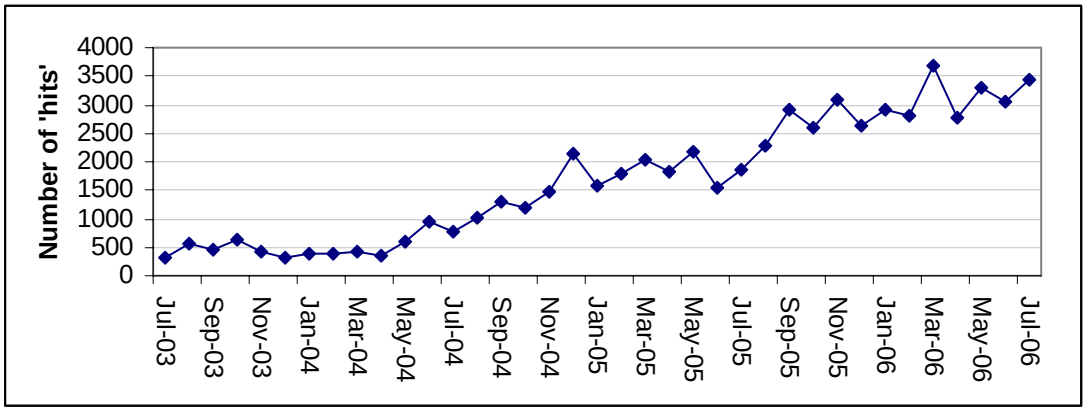
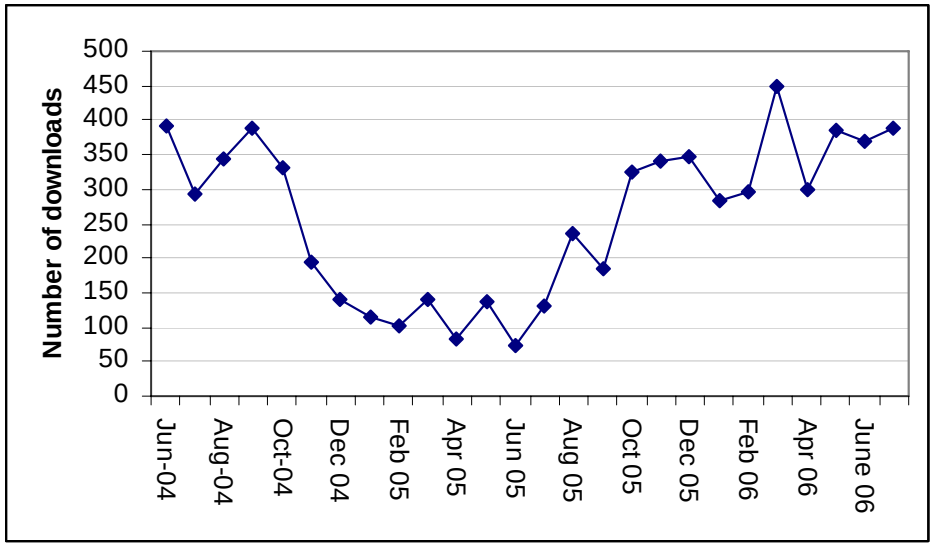


Figure 1 highlights that these pages have been increasing steadily in their interest to a peak of over 3500 'hits' in April 2006. This trend is to be expected, as more documents and links have been added to these pages. However, the number of monthly downloads suggests that the webpages have been an excellent mechanism of disseminating information about the CCP and palliative care research more broadly.

Collectively, the seven CCP evaluation bulletins were downloaded 11,152 times. Figure 2 shows the monthly downloads of all of the bulletins since the publication of the last bulletin in June 2004. Interestingly, whilst interest in these documents seems to have waned between October 2004 and July 2005, there was increased interest to a peak of approximately 450 downloads in March 2005. This may be attributed to the CCP project officers accessing these documents to assist them in writing their final reports.

Figure 2 Monthly downloads of the evaluation bulletins



Apart from the collective downloads of the CCP evaluation bulletins, the top five palliative care documents downloaded from the websites were:

- The palliative care evaluation guide with 6,118 downloads between August 200 and July 2006. http://www.uow.edu.au//commerce/chsd/Publications/palliative%20care_evaluation_guide_CHSD.pdf
- The CCP homepage with 5,590 'hits' between July 2003 and July 2006. http://www.uow.edu.au//commerce/chsd/caring_communities.html

- Emeritus Professor Ian Maddocks May 2003 presentation at the National Workshop with 5,544 hits between July 2003 and July 2006. http://www.uow.edu.au//commerce/chsd/caring_communities_workshop/Ian%20CCP%20Workshop.pdf
- The palliative care guide to ethical research[3] with 5,362 downloads between August 2004 and July 2006. http://www.uow.edu.au//commerce/chsd/Publications/palliative%20care_ethics_CHSD.pdf
- The PowerPoint presentation from the Collaborative Palliative Care in Rural Communities project in Launceston, Tasmania with 2,401 downloads between November 2004 and July 2006. http://www.uow.edu.au//commerce/chsd/Publications/ppt_Pall%20CCPCare%20Providers.pdf

Anecdotal evidence from the exit interviews revealed that project officers found the CCP website useful as a point of contact and support. It was also noted that the information available was extremely useful particularly from an evaluation perspective.

4.1.6.4 CCP Evaluation Bulletins

The Caring Communities Bulletins were developed by the NET to provide topical, relevant and regular information to the Caring Communities projects. Throughout the life of the CCP seven bulletins were produced covering a range of issues as follows:

Bulletin 1 An introduction from the national evaluators

Bulletin 2 An introduction to ethics

Bulletin 3 Qualitative research methods

Bulletin 4 Literature reviews

Bulletin 5 Indigenous issues in palliative care

Bulletin 6 Evaluation findings – the story so far

Bulletin 7 Second National Workshop evaluation

These bulletins are all available on the CCP webpage. The first five bulletins were formally evaluated and the results were reported in the first progress report. In summary, the bulletins were generally well received by the projects and considered a useful component of the CCP evaluation. The NET also received positive informal feedback about the bulletins in exit interviews with project officers.

4.1.6.5 Workshops

The idea of holding national workshops was first raised at a meeting with DoHA State and Territory officers in September 2002 and further explored by members of the NRG in November 2002. These workshops were seen as an ideal opportunity to:

- share ideas regarding activities across similar themes and within each State and Territory;
- network;
- build partnerships;
- nurture links that will help to ensure that the skills, contacts and expertise within the networks were effectively capitalised on; and
- educate project officers regarding the legal requirements, contract processes, marketing, self-promotion and evaluation activities.

[3] Masso M, Dodds S, Fildes D, Yeatman H and Eagar K (2004) *Ethical research in palliative care: a guide through the Human Research Ethics Committee process*. Centre for Health Service Development, University of Wollongong ISBN 0 642 82473 8 http://www.uow.edu.au/commerce/chsd/palliative_care.html

Two national workshops were organised and managed by PCA. The first workshop was held in Canberra in May 2003 and the second was held in Adelaide in October 2004. Professor Kathy Eagar and the NET facilitated both workshops. Both workshops were evaluated and the results of these can be found as appendices to *Caring Communities: report to the Australian Government on the national evaluation*.

Apart from these results, anecdotal evidence from exit interviews conducted with project officers revealed that there were mixed feelings about the first workshop. Most attendees agreed that it was an excellent opportunity to develop networks and meet with key stakeholders. However, a significant number commented that they found the workshop a daunting experience in relation to the evaluation challenges that lay ahead. Many participants agreed that it would have been better if an evaluation framework was already in place prior to the workshop. It was also noted that many of the project officers were not yet appointed at the time of the first workshop so missed out on the opportunity to learn from its lessons.

On the other hand, the second workshop was a resounding success. By the time of this workshop all project officers were established in their positions and gained a lot from the networking experience.

In view of the success of the second workshop, there was a recommendation to hold a third CCP workshop in approximately October 2005. However, in August 2005 DoHA's Central and State and Territory offices decided not to hold a third national CCP workshop. It was agreed that jurisdictional meetings or workshops could be held as necessary to cover issues such as networking, sustainability and preparation of final reports. It was also noted that the need to share information on project outcomes was being met by a number of projects in their presentations at the 8th Australian Palliative Care Conference in August-September 2005.

4.1.6.6 Site visits

The NET made 53 site visits between October 2003 and September 2005 (see Table 7). The purpose of these visits was to explain the evaluation framework, assist with ethics applications, facilitate networking between projects and provide general assistance to project officers.

Table 7 Site Visits made 2003-2005

State	1st report period (May - October 03)	2nd report period (Nov 03 – March 04)	3rd report period (April 04 – Sep 04)	4th report period (Oct 04 – March 05)	5th report period (April 05 – Sept 05)	Total Project Visits
ACT	2	1	-	-	-	3
NSW	6	3	1	-	1	11
NT	4	-	3	2	1	10
QLD	5	-	3	-	-	8
TAS	2	-	-	-	1	3
VIC	5	-	1	-	-	6
WA	5	-	3	-	-	8
SA	4	-	-	-	-	4
Total	**33**	**4**	**11**	**2**	**3**	**53**

The site visits were a very important part of the CCP communication and support strategy. They provided the NET with the opportunity to meet members of the individual project teams and work with them on a number of issues relating to the evaluation of their projects. In many cases, project officers had not been appointed by the time of the May workshop and these meetings were often the first face to face contact between the evaluators and the people organising individual projects. Project officers reported that they found the site visits important in establishing communication

links with NET. As one of them said 'as we had met face-to-face I felt comfortable about calling NET if I had a problem'.

During the visits the member of the NET explained the evaluation framework and the project members described their project plan in detail and how they intended to evaluate the different components of their project. The purpose of this was twofold. First, for the evaluator to ensure that the project was able to be evaluated and that the tasks the project plan outlined were clearly defined, feasible, and measurable. Second, for the evaluation team member to be able to advise on appropriate evaluation techniques and recommend sensible evaluation tools.

The site visits were reported as 'useful to get together initially' and gain an understanding of evaluation. One project officer reported that they were not employed when the site visit was conducted and recommended that visits be conducted after project officers have been recruited. Another reported that they would have like more visits from NET (even though there were no specific issues or concerns).

There was a high level of variation among the 37 Caring Communities projects with regard to the amount of support they required from the NET at these site visits. Generally, those projects which were managed by a team of people and had assistance from experienced researchers were less likely to experience problems in developing their project plans, maintaining and managing their projects and developing and conducting appropriate evaluation activities.

Also, projects situated in urban centres appeared to be more likely to be able to draw upon, and have sustained communication and assistance from, a range of experts. On the other hand, rural and remote projects had fewer resources to draw upon, they were more likely to have smaller teams and to have less experience in project management and evaluation. Therefore, these projects generally required a higher level of ongoing support. In some areas this was further compounded by communication difficulties, such as limited access to e-mail and Internet facilities.

The visits also provided an important step in facilitating networking and the sharing of knowledge between projects. In some instances evaluation tools were shared between projects. For example, the tools to measure Aboriginal and Torres Strait Islander peoples' knowledge and understanding of palliative care, which were initially developed by the Kimberley project, were used by many of the Aboriginal and Torres Strait Islander projects. In this way members of the evaluation team were able to link up similar projects, so that they would be in a position to share their knowledge and experiences.

In some cases, little follow up by the evaluation team member was necessary after the visits. However, a large number of projects required on-going support and assistance over the telephone, especially with the completion of ethics application and advice on the selection and use of appropriate measurement tools. In some cases a follow-up visit was required.

4.1.7 Ethics

The NET was granted ethics approval for the national evaluation of the CCP from the Human Research Ethics Committee (HREC) of the University of Wollongong on 30 September 2003. This ensured that the proposed methodology would conform to current ethical and data privacy requirements.

The NET also had an important role in determining the ethical requirements for each of the CCP projects. To facilitate this process, Evaluation Bulletin No 2 '*An Introduction to Ethics*' was published in June 2003. This guide included an Ethics Committee Checklist to assist projects in making their decisions about whether or not to apply for ethics approval. The NET was also able to advise whether individual projects required ethics approval at the site visits. Altogether, 24 out of 37 (65%) projects submitted ethics applications. Twenty three were approved and one project was informed by their local area health service ethics committee that approval was not required.

Of these 24 applications, nine went to the University of Wollongong HREC in the absence of a local committee.

For many of the CCP project officers, the process of applying to an ethics committee was a new process. Many of them provided positive feedback with regards to '*Ethical research in palliative care: a guide through the Human Research Ethics Committee process'* and also to the ethics checklist. Several project officers expressed their appreciation for the support received from the NET when navigating their way through the ethics procedure, particularly where an application was made to the University of Wollongong HREC.

4.1.8 Role of Palliative Care Australia

The Palliative Care Association (PCA) was funded to provide the following support services for the CCP:

- overall administrative support for the CCP
- secretariat support to the National Reference Group
- promotion activities e.g. managed the design, production and distribution of a CCP insert to their newsletter *Palliative Care News* – Autumn Edition 2004
- management of the selection and assessment process
- management of the two national workshops.

The PCA were mainly involved in the first half of the program.

4.1.9 Role of Australian Government DoHA officers

The CCP used a 'hub and spoke' model of project management, with the central office acting as the coordinating 'hub' and DoHA State and Territory officers (hereafter referred to as DoHA Program Officers) acting as the 'spokes' managing individual projects. Stakeholder interviews were conducted at the start, mid-way and at the end of the program with the DoHA Program Officers. Their comments and recommendations are included in this section.

The DoHA Program Officers were mainly responsible for managing the CCP funding in their jurisdiction. The execution of this role did vary, with some officers concentrating mainly on contractual management and others taking a broader role. Some DoHA Program Officers found it not easy accommodating CCP due to the lack of resources available at the State office level and the extra workload as expressed in the following quote. 'In future more resources i.e. extra staff, are required at the DoHA State level to provide assistance with networking'.

A CCP guide for DoHA Program Officers was developed to provide information on procedures to effectively administer funds and projects under the CCP. The DoHA Program Officers were responsible for establishing a selection panel in their jurisdiction to assess the CCP applications and select projects to be funded. Once the projects were selected, the DoHA Program Officers negotiated and prepared the funding agreements with successful projects. The six-monthly and final report templates were developed in consultation with the NET and the central office.

The DoHA Program Officers liaised and communicated with the projects in a number of ways, including:

- Email and telephone contact.
- Conducting visits to the projects. In some cases, the DoHA Program Officers accompanied NET on their site visits.

- Attending the national workshops. At the first national workshop, the DoHA Program Officers facilitated breakout sessions to discuss their roles and ongoing communication and support systems.
- Facilitating state forums or teleconferences.

One DOHA officer reported that initially communication between DoHA and projects was through regular face to face meetings with the project officers and the DoHA Program Officer at the state office. However, these became unpopular with the project officers as a result of the frequent staff changes at the Australian Government level, and communication later in the program took place via telephone or email.

After the initial program set up, the DoHA Program Officers were mainly involved in supporting the projects to ensure they 'got over the line' and met their contractual agreements. This included negotiating contract variations, often giving an extension of time, to enable projects achieve their aims and objectives and, in some case, providing additional funds for dissemination and/or communication activities.

The communication between the DoHA Central and State and Territory project officers included circulating regular information bulletins and holding quarterly teleconferences to update and discuss CCP issues. One DoHA Program Officer stated that the:

> 'National Office were also very supportive of DoHA's Project Officers and kept the officers informed of CCP developments through regular teleconferences, emails and correspondence. National office also managed various administrative elements of the CCP, particularly financial, that allowed DoHA Program Officers more time to manage their projects'.

The central office was reported as supportive by the DoHA Program Officers. However, two officers commented that the central office was not always aware of what was happening at a national level. An example given was:

> 'when a certain project was funded they found out afterwards that there was nearly an identical project funded by the Commonwealth and the CCP project had to change. This general lack of awareness led to problems of duplication'.

This hub and spoke model has proved effective in managing CCP. Another DoHA Program Officer commented that:

> 'some of the local palliative care grants are now being managed at the state level as a result of the success of the management of the CCP. The national office has learned the importance of engaging the state offices more. It is important to have a local face to meet with the organisations'.

The following comments arose out of exit interviews with project officers:

- **Change over of DoHA Program Officers**: There were comments from five States and Territories about the changing DoHA Program Officers. For example, one project officer liaised with three different DoHA Program Officers through the life of the project. The frequent changes in staffing affected communication with the projects and presented challenges in maintaining continuity of support for the projects. One project officer stated that 'a lot of time was wasted by the project in jogging the corporate memory of the Commonwealth in terms of what the program was about'. Another project manager and project officer overcame this potential problem by being proactive in contacting and briefing new DoHA staff when

necessary. Because of the high turnover of staff at state office level, the central officer had to brief new officers and repeatedly explain the role of the CCP and the evaluation.

- **Project support by DoHA Program Officer**: The majority of project officers reported that the DoHA Program Officers were very supportive and helpful. In fact, a few project officers reported that not only was there good support from the DoHA Program Officer but they also took a personal interest in the project. Two project officers reported that they received no support from the DoHA Program Officer. However this was not a problem as the project officer 'just got on with the job'. Another comment was that 'the support received from DoHA varied with the personality of the DoHA Program Officer – some were more helpful than others'.
- **Project content knowledge**: One project officer reported that the DoHA Program Officer had no content knowledge of the projects (turnover of three officers in time of project) whereas another project officer felt that the DoHA Program Officer provided feedback that was encouraged and specific to the project, indicating that he/she had read the project's report thoroughly.
- **Contact between DoHA Program Officer and projects**: A few projects commented positively regarding the DoHA Program Officer taking time to attend meetings. For example, one project reported that the DoHA Program Officer had attended a steering committee meeting and met people on the committee. They also visited at the end of the project regarding getting extra resources. It appears that some of the project officer benefited from the face-to-face contact and liking the personal contact that enabled them to build a good rapport. 'It was useful to have the DoHA Program Officer local as I felt more likely to call and easier to access, more informed and connected to the project and program'.

4.1.10 Role of State and Territory government officers

Jurisdictional government officers were involved early in the CCP, as members on the selection panels, and provided links between projects and existing palliative care services. For example, one jurisdictional officer used their knowledge of specialist service delivery to link projects up with health care providers. In addition, the jurisdictional officer provided experts to train staff in one project, which increased the capacity of that project. The jurisdictional officers attended the first and second national workshops, where they were able to meet with the projects funded in their state or territory.

There were a number of jurisdictional teleconferences and meetings coordinated by the DoHA's State and Territory offices. Jurisdictional officers attended some of these teleconferences and meetings. Some jurisdictional officers were regularly kept informed on CCP projects by the DoHA State officer. Others were contacted on an as needed basis.

The majority of jurisdictional officers were interviewed by the NET at the start of the program and some at the mid-point. It was apparent by the second round of interviews that the jurisdictional officers were less able to contribute to the program evaluation, in part due to staff turnover, and hence interviews were not conducted at the conclusion of the program.

Following are some comments and recommendations made by jurisdictional officers made about aspects of CCP.

- **Application guidelines**: A recommendation by two jurisdictional officers for DoHA to provide clear guidelines to support the application for funding process.
- **Role Guidelines**:

> 'It would have been helpful if DoHA could have provided a clearer definition of the role and responsibilities of state officers in relation to the CCP. Confusion over roles may be due to the fact that expectations of the role of state governments seem to have changed over time'

- **National Evaluation**: One jurisdictional officer commented that the evaluators should have been engaged earlier in the program so that they could assist with aims and goals of each project.
- **Funding Allocation**: One recommendation was that a preferred method of funding allocation could be for DoHA 'to 'sit down with the states', give the states/territories a clear idea of how much money is available and then work out, between state and DoHA, the best way of spending the money. Accepted that, in part, this may have been achieved by involvement of predecessor in selecting the successful projects'.
- **Program planning**: There was concern raised by some jurisdictional officers that 'a lot the CCP projects are 'ad-hoc' and do not necessarily fit well with the palliative care priorities in the State/Territory'.
- **Sustainability of projects**: At least three of the jurisdictional officers were concerned about the sustainability of the projects. That is, 'CCP projects have set up a whole series of expectations that can only be met by ongoing funding and therefore sustainability of the improvements made by the projects is problematic'. In addition, one jurisdictional officer reported that, during the second national workshop in Adelaide, there may be some confusion about the role of state health departments in providing ongoing funding for CCP projects after the program finishes. They pointed out that the state had no capacity to provide ongoing funding as provision of basic services had to take priority.
- **Project contributions**: One jurisdictional officer felt it was difficult to say how the projects have contributed overall. They are very different from each other, with different aims and settings. This was seen as 'one of the consequences of a 'scattergun' approach to program funding. With such an approach it is hardly surprising if a program does not achieve much cohesiveness in terms of outcomes'.

4.1.11 Role of the National Evaluation Team

The key roles of the National Evaluation Team (NET) were:

- developing the evaluation framework and methodology
- conducting the site visits and ongoing risk assessments
- facilitating the national workshops
- supporting the projects
- communicating with the Central and State DOHA officers
- conducting the program level evaluation.

Much of this work is reported elsewhere in this report.

The evaluation had both summative and formative components. In some instances members of the NET felt that they were able to add value to the projects and the program by becoming part of the 'intervention'. For example, on sites visits it was sometimes appropriate to assist with the rewriting of project plans to enable the evaluation to occur. On other occasions assistance was provided in the design of evaluation tools, such as a training session survey. The NET also assisted some projects to write ethics applications.

Consistent with the formative role of the evaluation, the NET judged that it was more important to assist projects to get over hurdles than to merely report on those hurdles. This involvement arose either by opportunity (in the right place at the right time) or by request. The NET also played a role in linking projects together and/or sharing project outcomes across States/ Territories and in some cases across programs e.g. with Rural Palliative Care projects.

Exit interviews were conducted at the conclusion of each project, usually with the project officer or project manager, and included one question about the role of NET.

Many project officers commented that the NET was accessible and that support was available when it was required – they were 'very pleasant' and 'down to earth'. Some commented that this was in part due to meeting NET members face-to-face during site visits and at the national workshops. Some project officers reported needing little support from the NET due to the stability of the project team, good local support and involvement of an independent evaluator.

One project officer stated that the terminology used in the sustainability, capacity building and generalisability tools was not common knowledge for them, with another commenting that they 'would have liked more information on how use the evaluation tools'.

4.1.12 Reporting requirements

4.1.12.1 Project plans and six-monthly reports

The site visits highlighted that there was considerable variation between the DoHA State and Territory offices in the requirements relating to the detailed project plans. This resulted in some tension among those projects that considered that they had to submit more detail than others. These perceived problems, and the need for consistent and comparable data, resulted in the NET working with the State/Territory Offices to produce a standard template for the projects' six monthly reports. The NET reviewed the reporting templates provided by each of the State/Territory DOHA offices and combined the essential elements of these in a concise and logical format. To this was added a section where projects were asked to provide details of their evaluation and dissemination activities. The reporting template was completed in September 2003 then provided to each State/Territory DoHA office.

Despite a common template being produced by the NET, the way it was completed varied across the jurisdictions. For example, some projects completed the report by exception, meaning that they only reported changes to the project plan. Rather than just reporting for a set six month period, some six-monthly reports expanded on the previous six-monthly reports. This made reviewing the six-monthly reports difficult because it was hard to separate the tasks within each reporting period.

Some projects commented that they would have liked feedback on their progress reports. One project suggested that the NET could have reviewed the six-monthly progress report and then had a teleconference with the project officer to discuss the report. It was felt that the NET would have obtained more details with a follow up teleconference as sometimes the text originally written by the project officer was edited to meet organisational requirements. Because the reports were seen by the host organisations there was also the potential for self-censorship by project officers regarding issues such as lack of organisational support or the need for training to build their own skills.

A few project officers reported that the six-monthly report, though detailed and time consuming, was a useful task.

> 'The six-monthly reporting template was useful, I was able to put my work plan into the report format very easily by breaking it down into six-month segments, each with several objectives. Then when it came time to do the report I worked through them. There was a certain amount of work attached to the reporting but it was not massive'.

One project officer felt that the 'bureaucratic insistence on accountability through mindless amounts of paperwork was paralysing' and gave their preference for an outcome based contract and outcome based evaluation strategy rather than a fixed workplan (which, in this case, had been drawn up and submitted to DoHA as part of the funding application prior to the officer's

commencing in the position). This person may not have realised that it was possible to apply for a contract variation to change project goals or timelines. In one State the DoHA officer remarked that most projects had successfully applied for contract variations to enable them to evolve and refocus to ensure good outcomes, and she viewed this as positive.

A difficulty reported by a DoHA officer was the poor standard of reporting. Payments were held up because the reporting was not clear with regard to meeting projects' aims and objectives and so the officer had to spend time clarifying these issues. Another DoHA officer reported that it was difficult to obtain the audited financial reports from each project, which was part of the six-monthly reporting requirements. This was because the projects had not budgeted for this task and/or their organisations did not use external auditors.

4.1.12.2 Final report template

It was agreed by participants at the second national workshop that a common template should be produced to assist CCP project officers to write their final reports and that the template should be based upon the 'knowledge transfer' approach developed by the Canadian Health Services Research Foundation. This involves framing the report in a reader-friendly format referred to as a '1:3:25'. It consists of a one page summary of the projects' main messages, a three-page executive summary written in a style that 'meets the needs of the busy decision maker', and the complete report, which should be no more than twenty five pages long. Further information relating to this style of writing can be found at http://www.chsrf.ca/knowledge_transfer/pdf/cn-1325_e.pdf.

Subsequently, the DoHA provided the NET with a template previously used by another section of DoHA and this was adapted to comply with the 1:3:25 format. The first draft was circulated amongst the DoHA State and Territory offices on 31 January 2005. In addition, three sites exiting the CCP were asked to 'road-test' this version. Following feedback, it was decided to simplify the format. This was undertaken by the NET and the final reporting template disseminated on 21 February 2005.

The final report session at the second workshop was described by one project officer as 'a very useful discussion about the final reporting template and expectations'. This discussion assisted the project officer to gain an understanding about format and the dissemination of the three sections.

Some project officers reported that the final report template was very useful. A few project officers found the template 'restricting' as there were set questions with little more for additional information. However, not all projects used the 1:3:25 format to document their final report. In addition, there was variation in the way that the evaluation findings were reported. In some of the final reports the evaluation section was not completed. Other reports included an evaluation section but it was poorly documented and there was not enough detail recorded, e.g. only reported details on the process of the evaluation and not the results.

One project officer suggested that an overview on the reporting requirements (progress reports and final reports) from the start of the program would have been beneficial. Another project officer found it very difficult to get the final report completed. They had not allocated enough funds to writing up the final report.

The final reporting template was also adopted as a way to assist projects disseminate their achievements. It may be pertinent in the future to follow up if the 1:3:25 format was useful in disseminating the results across different audiences. For example, did projects post or distribute their main messages (1) and if so, what were the outcomes? How many people read the executive summary (3) versus the full report or main message? Who read the full report (25) and did they use the results and learning from the reports in their work?

One DOHA state officer commented that the challenge is how to use the evaluation and the final reports. Ultimately the impact of the CCP will depend on how well the lessons learned from the program are disseminated and result in policy changes at the system level.

4.2 Project-level strategies and processes

This section of the report focuses on findings regarding the processes at the project level which enabled and supported projects to achieve their goals. Aspects of project planning and needs analysis are dealt with first, followed by community engagement and project management issues. The difficulties facing projects, and finally the processes of evaluating the projects, are discussed. This section draws on data from the project exit interviews, project summaries and stakeholder interviews.

4.2.1 Project goals and objectives

Most of the projects chosen from the original field of 270 applicants were well defined with coherent objectives and strategies. They were designed around the fact that the CCP had a three-year life span and a certain amount of funds, and there were realistic expectations about what could be achieved within those parameters. Some projects had several streams or components and these were particularly challenging for the project officers. It was an advantage to have a project partner with experience in project design.

It was important to ensure that everyone involved had a shared understanding of what the project was about. Misunderstandings could arise, for example, when the project officer had not been involved in the design and planning phases. In one project, the project officer had been taken on in a role previously filled by a volunteer, and the people who designed the project neglected to tell the volunteer about it. This failure of planning later had an impact on the sustainability of the project's achievements.

If the project officer's role was not clearly defined, they ended up doing things outside their brief. This inevitably led to problems with excessive workloads as the officer struggled to complete project deliverables such as reporting while taking on other tasks they considered extremely important. For example, some project officers with clinical experience in palliative care found it difficult to resist the temptation to become directly involved with clients.

There were also cases where the project funds were seen quite differently by the host organisation and the funding body. In one case the project managers saw the grant as a valuable way to top up or maintain an existing service, rather than to set up a discrete project. The host organisation was quite resentful of what it saw as pressure to report outcomes.

4.2.2 Community needs addressed by the project

Successful projects were well focused because they began with a careful needs analysis, or a literature review, or consultation in the local community. Sometimes several of these strategies were employed. Some examples of good practice are:

> 'To ensure that GPs gained maximum value out of their placements, they were encouraged to prepare for them. They were given reading materials and written tasks (including a case scenario) and were asked to list some topics (possibly relevant to their own caseload) that they wished to learn more about. In this way, the placements could be tailored somewhat to each GP, avoiding the disappointment of unmet expectations.'

> 'A literature review was conducted to investigate the role and education needs of care workers providing palliative care in the home setting. Interviews and focus groups were held with clients receiving palliative care, carers, care workers, allied health professionals and care coordinators to help determine the role of care workers in palliative care.' (This was a project developing an education package for community care workers.)

> 'The education that was delivered was based on focus groups to determine needs. As a result of this it was considered to be very relevant by the staff.'

Several projects were very successful in meeting their objectives of recruiting and training palliative care volunteers but then found there was little demand for their services. Clients were difficult to contact, gatekeepers such as palliative care specialists were slow to start recommending the volunteer service, or the volunteers themselves were unwilling to travel far because of rising petrol prices. Some frustration was expressed by volunteers who had undertaken training and then did not get the chance to put this into practice.

On the other hand, some projects were able to make subtle changes to their objectives and methods to ensure the outcomes would be relevant and useful. Several found that other, similar projects or services had been implemented locally and reassessed the need for their own project. In one case, a local health service employed a nurse to provide outreach services in palliative care, something the project was also planning to implement. In response, the project team refocused on coordination and referral to services, which they identified as an area of need.

Some of the DoHA officers actively encouraged this process of refocusing projects on more relevant and realistic goals. For instance, one commented that a certain amount of flexibility in contract management was important and kept the projects getting results. This officer noted that most of the projects in that State had contract variations to extend or change the project plan to ensure results, and regarded this as positive.

4.2.3 Engaging stakeholders

It takes a great deal of time and effort to build networks – as one project officer explained, community engagement involves 'going at their speed'. This slow pace may not conform to the project timetable.

For these community-based projects, engaging stakeholders was a make-or-break task. This is because they were about making connections between providers, coordinating care, establishing referral pathways or implementing new models of care. Some drew on the expertise of providers to create resources or provide education and training; others mapped local resources. It could be argued that these kinds of connections were among the most important achievements of the CCP, above and beyond the specific goals of individual projects. The success of community engagement has implications for the sustainability of the project or at least its outcomes in the medium term, a point summed up neatly by one DoHA officer:

> 'Raising awareness, developing communication between providers, developing links and referral pathways and developing resources/ information distribution are much more sustainable after the funding ceases than the direct service provision to the clients. Most importantly it breaks working in silos which is often a big mistake and prevents sustained improvement in services.'

Steering or reference groups for the projects were generally made up of stakeholders from the community. These groups played a valuable role in creating and maintaining networks of support and gaining access to resources (e.g., potential recruits for volunteer services or for studies, distribution networks for promotional materials, relevant literature and clinical expertise, parking permits for volunteers visiting a hospice). The reality, however, was that these people were volunteers and were often very busy and some projects found they were not as involved as they had hoped.

The important role of steering groups was also mentioned by several of the DoHA officers in their interviews at the conclusion of the CCP. One felt that a characteristic of successful projects was a good steering committee made up of representatives from relevant local organisations that

supported the project throughout its lifetime. Another said that local leaders or 'champions' who helped build the profile of the project provided essential support:

> 'Where project workers worked in isolation, in a sense, or did not have that organisational support behind them they tended to struggle. Where the project officer had to develop their own links with local networks as well as doing the project itself – that's a big ask for someone at the level of a project officer to do.'

Engaging with Aboriginal and Torres Strait Islander communities requires a long-term commitment to building relationships of trust and integrity. Many of the issues were common, particularly to the rural and remote projects, such as dealing with staff turnover, identifying local champions and achieving genuine, ongoing consultation despite the distances involved. One project summed up the challenges:

> 'Project staff ... found it difficult to recruit local people to act in a cultural liaison role who were prepared to talk about death and dying. The project also experienced a very high turnover of staff and each new person had to start from the beginning in developing relationships within the community.'

Keys to maintaining relationships with stakeholders included regular contact via meetings or emails or newsletters and keeping an up-to-date list of names and addresses. Some projects started by compiling a register of local service providers and other stakeholders. One project officer remarked on how important it was to get agreements in writing, as this helps to buffer the project against staff changes in stakeholder organisations:

> 'One thing I found was that when there were changes in the senior staff of the agencies we dealt with, we often had to start again with negotiations. If I did this again I would get written agreements. I learned that you need to get things in writing, especially when you are dealing with change.'

Even when project officers had worked very hard to get stakeholders involved and on side, unforeseen problems could derail their plans. They talked about issues such as the need to 'respect territory' and 'don't step on toes'. In a competitive atmosphere it was essential for the project to be seen as a 'neutral party'. One project manager said:

> 'The main difficulty was overcoming competitiveness and lack of trust between organisations which prevented the sharing of ideas and resources … The fact that (host organisation) was not a competitor and the (project) was needed and filled a gap worked to the project's advantage, as did the persistence and people management skills of the project team.'

Project officers spent time building trust, negotiating and finding common ground between stakeholders. This was more difficult where there was a great deal of change happening in the palliative care sector, or more generally in the health system.

> 'I found myself as the 'middle man' between clinicians and managers, each with their own agenda … There was a constant need to act as the link … because of the plethora of changes taking place … Everyone involved in the change process 'has to have their say'.

It was not always possible to detect tensions between groups, especially where projects were working with rural or remote service providers. For example, one project organised an education session at a community health centre (because the nurses offered it as a venue) and travelled for many hours to reach the town only to find that none of the hospital staff would come because of a territorial dispute with the local community health staff.

Several projects that dealt with stakeholders over long distances or in large regions commented on the need to find a local champion to look after the interests of the project and maintain momentum:

> 'The key was to get access to one person who would take ownership of it on the site. That is hard to achieve because of course the other fact of life about rural and remote health is that staff turnover is very high, so there is a lack of corporate memory.'

4.2.4 Project management: what worked?

The way in which projects were managed naturally had a substantial impact on their potential to achieve successful outcomes. The CCP projects were small in scale and were generally staffed by one key officer. Sometimes this person was supported by a small team, which might include hands-on help with administration, budgeting or networking. Some project officers commented on the fact that project management took considerable time and effort and should have been included in the original project budget.

Because the projects had so few staff, the skills, experience and enthusiasm of the key project officers were crucial to their success. Diverse technical expertise was required, including project design, data collection and analysis, report writing, and specialist skills such as designing websites, promotional materials or education packages. Some of the project officers also had high levels of clinical knowledge and experience in palliative care. In addition, they required skills in project management (e.g., running a budget), negotiation and community engagement. This was a great deal to ask from one person, especially as many were employed on short-term contracts.

From the perspective of the DoHA officers, projects that lacked good organisational support from a 'mature' and well-resourced host agency were likely to struggle with deliverables such as reporting and evaluation. The types of support required by projects included administrative assistance, access to organisational systems, supervision or line management, advocacy and leadership. It was felt that the continued 'championing' of the project by a person with influence within the organisation would increase the likelihood of sustainability of the project after its end date. Particular problems arose where project officers were located in isolated rural facilities or where the host organisation was large and multi-layered. Stable line management, which provided opportunities to debrief, was particularly important in remote areas.

There was at least an initial advantage for projects where the officer was already employed by the host organisation and took part in designing the project. Where necessary, providing project officers with training (e.g., in project management) was a good investment.

Another useful approach was to bring in outside expertise. For example, some project officers who were conducting internal evaluations sought advice from local university staff who could help them design the evaluation strategy. Considering that the loss of a project officer part-way through the project was potentially disastrous, it was a sensible strategy for the host organisation to be generous in providing practical, professional and psychological support.

Indeed, good relationships between project officers and their hosts could create mutual benefits. Employing an experienced project officer is an opportunity for the host organisation to build its own capacity, and the recognition of their skills makes the project officer feel valued:

> 'The project officer had a great deal of research experience but the managers did not … so for them it was a chance to learn about the processes of running the project, sharing resources and networking. In the course of conducting the project, the officer was able to pass on some of her knowledge and skills in research to the managers.'

Time management can be a challenge, especially for project officers who are already part of the host organisation and take on the project part time in addition to their previous role. It is hard to predict in advance just how much time a project is going to take so there needs to be some flexibility in these situations. Project officers talked about the need to be able to 'borrow' from one job and 'pay back' the time later.

Extra support is needed for those in rural and remote areas. These were the projects most likely to be at risk due to difficulties with staff recruitment and turnover or lack of support in the host organisation. Finding ways to provide this support is an ongoing challenge for program managers.

It is essential to have systems in place to monitor progress. Not only does this keep the project on track, it also enables managers to assess whether the original budget and time frame was realistic and to be able to approach the funding body for an extension if necessary. While a few project officers saw the six-monthly reporting template as a bureaucratic nuisance, others were able to use it to their advantage. Project goals, objectives and strategies could be entered into the template along with their associated time lines. The six-monthly reporting schedule provided an opportunity for project staff to reflect on their achievements and to consider whether strategies were effective. If progress was slower than expected, they could consider changing their methods or asking for more resources.

In addition, host organisations must ensure that work completed is documented adequately so that they are protected if a project officer chooses to leave during the course of the project. Progress reports and other documents recording the work completed to date, contact lists, background information and so on provide an essential resource for any incoming project officer. Where possible, host organisations should implement a formal handover process. If staff changes are not handled well, much time is lost as new staff start from scratch in gathering information and building networks.

Adapting to the environment was a key strategy for success. There were many examples of projects that encountered unexpected difficulties, such as the failure of the original recruitment methods, or the unfortunate coincidence that some other service had just started doing what they were planning to do. In order to achieve their outcomes, they were forced to innovate and adapt. For example, several of the projects that provided specialist palliative care awareness training to primary care providers found it was very difficult to get General Practitioners involved. One project got around this problem by offering the GPs a one-to-one appointment for academic detailing, rather than a workshop. This was such a successful approach that the project continued and expanded it. Another example of good practice came from a project that aimed to recruit volunteers:

> 'The original strategy (using the community awareness survey) failed and so the project team had to find other ways to recruit volunteers. They found that the best form of communication, especially in rural and regional areas, was the placement of fliers in places where people were apt to gather and talk (e.g., at hairdressing salons, in shop windows), and also to give presentations to existing small community groups (e.g., Lions, Probus, U3A, Independent Retirees, School Guidance Officers). Based on previous experience with community type programs the team acknowledged that this strategy could only succeed if sufficient support (resources, training, help) was provided to the new recruits, otherwise the interest dissipated very quickly.'

4.2.5 Difficulties and barriers

Distance and isolation presented major challenges for projects operating in rural and remote areas. Project officers had to travel extensively to provide training or support or to engage with stakeholders, and this travel was time consuming. It was more difficult to build and maintain

support networks for the projects when communication was restricted to telephone and email and there were few opportunities to meet face-to-face.

Some of the rural and remote projects had their main focus on increasing the capacity of the palliative care workforce. Although feedback from the education sessions provided by these projects showed high levels of satisfaction and increased knowledge of palliative care, it is uncertain if and how this information was translated into improved outcomes for consumers. Rural and remote communities are characterised by very high staff turnover, and it is possible that staff moved on to other positions before their knowledge was ever utilised in the care of their patients.

Projects that sought to engage with Aboriginal and Torres Strait Islander communities faced many of the difficulties common to rural and remote areas, plus additional challenges in community engagement. Many of these projects provided additional services as well as enhancing community understanding of palliative care. Some were very successful. For example, a project in the Kimberley region of Western Australia (WA-1) produced a range of educational resources and worked to increase the level of care and services that people received in remote Aboriginal communities. Other projects faced so many barriers in actually engaging with Aboriginal people, that it is difficult to know if there was any successful exchange of palliative care information. Underlying most of the Aboriginal and Torres Strait Islander projects was a lack of knowledge about Aboriginal and Torres Strait Islander needs regarding palliative care. It was unclear whether the difficulties in community engagement were due to the fact that people had so little access to information and resources that they were unable to articulate their needs, or whether in fact palliative care was regarded as a relatively low priority.

Many projects targeting Aboriginal and Torres Strait Islander communities attempted to cover a very large geographical area, and sometimes multiple language groups. Given the high cost of travel to communities, difficulties regarding access, difficulties regarding effective communication and perhaps limited community enthusiasm, is likely that effective consultation regarding the highly sensitive issue of palliative care was extremely limited.

In some cases the remoteness of the project contributed to difficulties in recruiting and retaining project staff. But there were other contributing factors as well. For instance, in NSW there was a reorganisation of the Area Health Services associated with some job losses and staff freezes. This made people reluctant to move temporarily out of a role to take up a project position in case the job was not there when they wanted to go back.

Difficulties were also encountered with human and other resources within the host organisations. Because these were small-scale operations, the illness or personal crisis of one member of staff could have a disproportionate effect on the achievement of project goals according to the timetable, as could a lack of key skills (e.g., evaluation, budget management). These kinds of difficulties were exacerbated when the project was basically a ‘one man band’ with little support from the host organisation. Where the project was incorporated into the organisation’s goals and objectives and had strong support from people with power within the organisation these kinds of problems could be overcome.

Some opportunities were missed because project staff did not recognise the value of evaluation, or did not realise that part of the project budget could be used to fund an external evaluator.

A few projects had overly ambitious goals, or their expectations were unrealistic. Recruitment of participants and/or engagement of stakeholders was commonly much more difficult than anticipated. When their proposed methods for community engagement failed, some projects were able to adapt and innovate, with excellent results.

4.2.6 Project evaluation

There were different responses to the requirement for project and national evaluation. Some project officers had incorporated evaluation into their original proposal and plan and saw it as

essential and integral to the project. They believed it was important to obtain baseline information and to monitor the progress of the project in order to provide feedback to staff and the community. A rigorous evaluation process provided an opportunity to identify and acknowledge successes. Positive responses included:

> 'The results from the evaluation also fed back into the development of the project. In this way it was a true action study, with a continuous cycle of improvement.'

Others felt that the evaluation had been imposed on them, that they now had to allocate valuable time and money that could have been used for 'doing things' to something bureaucratic and intrusive. In some cases, active resistance to evaluation and reporting meant that evaluation strategies were implemented mid-way through the project and the opportunity to collect baseline data was lost. However, with help from the NET and DoHA officers, most projects that were resistant were able to collect evaluation data and therefore report outcomes.

In many cases, project officers came to see the value of evaluation as time went by, when they realised that the data they collected could be used to demonstrate the effectiveness of their project and therefore to support applications for future funding. Evaluation processes were described as time-consuming but interesting, as they provided an opportunity to clarify goals and reflect on achievements.

There were some unexpected findings which led to follow-up projects with similar goals to other CCP projects. For example, feedback from the GPs who completed palliative care placements in one project indicated a need for better support for palliative care in residential aged care facilities. The project officer used these data to apply successfully for funds to employ a palliative care nurse to liaise with and educate staff in aged care.

Although all projects were expected to allocate 10% of their budgets to evaluation, only six took up the option of engaging an external evaluator. For these projects, external evaluation was an excellent investment. It separated the evaluation tasks from the project tasks, freeing staff to concentrate on making the project work, and ensuring that the evaluation tasks were given priority. There was also the potential for some transfer of knowledge and skills from the evaluator to the project team. Importantly, external consultants brought independent perspectives to the evaluation of the projects. Even where the project staff were experienced in evaluation, they commented on the value of having feedback from a detached observer:

> 'Two years on into the project you are quite close to your work. To have someone else scrutinise your work and give feedback is invaluable. I think the project has greater credibility due to our having an external auditor who evaluated it.'

Some of the most challenging projects to evaluate were those that focused on building community understanding of palliative care, because often these evolved as they went along, trying various methods until they hit on one that worked. It was sometimes difficult to pin down what the outcomes were for these kinds of projects, but good project evaluations documented the processes clearly and made a systematic attempt to assess impacts.

Another challenge related to the difficulty of evaluating impacts on palliative care clients and their families. As indicated above, few projects were able to measure and report direct impacts. One project had originally planned to survey clients and carers, but was not able to recruit a large enough group to enable a statistical analysis of the data. The project officer consulted with an external academic before designing a qualitative evaluation involving interviews (QLD-5). Another project rejected survey methods for a similar reason, but found that interviews were not feasible either, because so many clients had died or were not interested or able to take part. The project

redefined its ‘customers’ and re-focused its evaluation on stakeholders who were one step removed from palliative care patients (QLD-4).

Several project officers commented on the value of keeping a diary or journal and recording comments about telephone conversations, meetings, education sessions or ideas throughout the course of the project. These provided a valuable source of data about project processes and impacts (e.g., QLD-4, NSW-9).

Some evaluations covered only part of the story, because they had not considered the whole range of outcomes that could be expected, or the value of thinking about project processes and learning from those experiences. Another challenge, especially where projects had adapted to fit with the environment and address community needs, was keeping the intervention consistent enough to enable an evaluation.

It should be noted that no funds were allocated for a longer term follow-up of any of the projects or to ensure that findings or resources produced (e.g., manuals, protocols and policies) were subjected to peer review. The peer review process is a widely accepted method for assessing the quality of research and evaluation findings. Reports and other documents that are not peer reviewed may have limited impact in their field as they are less accessible and less likely to be included in syntheses of relevant findings. Several projects were able to produce peer-reviewed publications that placed their evaluation findings before a wider audience.

5 Discussion and Conclusions

5.1 Impact of CCP

The CCP took an approach of 'letting 37 flowers bloom' by funding a variety of projects across the country and establishing a formal evaluation to identify what worked and what did not work. Without wishing to push the gardening analogy too far the key issue is whether the resultant 'flowers' are merely 'annuals' that will fade away at the end of the season or something more permanent that will continue to grow and develop.

The focus of the CCP was on building the capacity of providers, raising awareness of palliative care in the community and forging partnerships between local stakeholders. Not surprisingly, the result is that there is little evidence that the CCP had much direct impact on consumers (patients, carers, families). This was due in part to the lack of emphasis in this area and the scanty nature of much of the evidence but also to the difficulty of identifying impact within the constraints of what were, for the most part, relatively small projects. It is plausible that many of the projects (e.g. education of providers) would improve the quality of palliative care and hence have an impact on consumers but this was simply not tested in most of the projects.

Many projects involved education programs for health professionals, volunteers or carers. One of the issues with such programs is the different ways in which impact can be evaluated. The most common method is to conduct 'before and after' evaluations to identify whether there has been an increase in knowledge as a result of the training program, typically soon after the education program has been completed. This approach was the most common one adopted by CCP projects, which is to be expected. However, there are limitations, primarily the lack of long-term follow-up to identify whether knowledge has been retained and the absence of any understanding of whether increased knowledge has resulted in improvements in practice (by health professionals, volunteers or carers). It takes considerable time and energy to develop a good education program and, in some cases, this consumed a major part of the project, with little time and resources left over to assess impact.

What the CCP has produced is a considerable volume of material in the form of education programs, manuals and documentation regarding new models of care, although the true value of these materials is not immediately evident. For example, in the case of the latter, two models of care for employees (VIC-1) and rural palliative care (TAS-1), were developed over the course of the project but were largely untested by project completion. This begs two important questions:

- What is the quality of those materials?
- How can others use this material, saving themselves the trouble of 'reinventing the wheel'?

Peer review is a widely accepted method for assessing the quality of research and evaluation findings. The same approach could be adopted with regard to the CCP materials i.e. having an expert body review the materials, seeking modifications if necessary, and then making those materials available to the community of palliative care practitioners. The data on downloads from the CCP website indicates that locating these materials in such a location can be a very useful form of dissemination. Care Search is the obvious choice.

In keeping with the objectives of the CCP many projects involved networking and strengthening partnerships of one form or another, either to improve links between providers or the community more generally. While evaluation of such work was patchy, it certainly provides an important foundation for future work, which, as in so much of the work of the CCP projects, raises the issue of sustainability. The governance structure of many projects e.g. steering groups and/or reference groups, assisted this process.

5.2 Program management

The relatively small pool of palliative care practitioners available to participate in the selection of CCP projects resulted in some potential conflicts of interest, although this is not unexpected. The broad nature of the CCP was reflected in the selection criteria which resulted in many different types of initiatives having the potential to be funded, presenting difficulties for those involved in the selection process. A more targeted approach might have made selection easier but would have been inconsistent with the CCP. There was a perception in some quarters that metropolitan projects were funded more generously than their rural/regional counterparts but this may have been a factor of population demographics than anything else.

In general, the process of DOHA state officers taking on the role of managing the CCP in each State and Territory worked well. In cases where this did not work so well it was primarily due to staff turnover. Joint visits to project sites by DOHA state officers and members of the NET proved to be beneficial and helped clarify the roles of the respective parties. Project staff appreciated the support of the DOHA state officers.

The second national workshop was arguable the single best initiative to contribute to the CCP as a program, rather than just a set of discrete projects. Participants shared ideas, developed networks and valued the presence of all parties – project staff, DOHA staff (central and state/territory offices) and the evaluation team. The CHSD website proved to be the most valuable dissemination strategy.

5.3 Project management

The small nature of many projects presented both opportunities and challenges. Smallness can lend itself to 'getting things done' quicker and more effectively than in larger projects but results in critical dependency on one or two key people. Illness, absence or departure of one person had a detrimental effect on several projects, resulting in either delays or non-achievement of objectives.

For projects in rural and remote areas the tyrannies of distance and isolation presented major obstacles. Project officers had to travel extensively to provide training or support or to engage with stakeholders, and this travel was time consuming. It was more difficult to build and maintain support networks for the projects when communication was restricted to telephone and email and there were few opportunities to meet face-to-face. In some cases the remoteness of the project contributed to difficulties in recruiting and retaining project staff.

Many projects in remote locations had a strong focus on improving palliative care for Aboriginal and Torres Strait Islander communities, making it difficulty to isolate what issues were common to 'remote' projects compared with 'Aboriginal and Torres Strait Islander' projects. Although engagement of Aboriginal and Torres Strait Islander consumers, providers and communities calls for specific strategies and requires a long-term commitment to building relationships of trust and integrity many of the issues are common e.g. dealing with staff turnover, identifying local champions and achieving genuine, ongoing consultation despite the distances involved. Our considered opinion is that, while CCP projects with a focus on Aboriginal and Torres Strait Islander issues faced particular challenges, remoteness is far more problematic.

Projects managed by a team of people with assistance from experienced researchers were less likely to experience problems in developing their project plans, maintaining and managing their projects and developing and conducting appropriate evaluation activities. Projects in urban centres were better able to draw upon, and have sustained communication and assistance from, a range of experts. Rural and remote projects had fewer resources to draw upon, were more likely to have smaller teams and had less experience in project management and evaluation.

There is an inherent 'Catch-22' with regard to projects in remote (and to a degree, rural) communities. Without 'trying things out' it is difficult to know what works and what does not. Yet

remoteness, based on our experience with the CCP projects, does not lend itself to experimentation – it is so big a hurdle that it is very difficult to get a project started, much less sustain a project over the course of project funding.

Project management had a substantial impact on project outcomes. The CCP projects were small in scale and were generally staffed by one key officer. Sometimes this person was supported by a small team, which might include hands-on help with administration, budgeting or networking. Some project officers commented on the fact that project management took considerable time and effort and should have been included in the original project budget.

The skills, experience and enthusiasm of key project staff were crucial to success. Much of the work required project management skills, which are not easy to obtain and tend to be in short supply. Those projects that engaged their own (local) external evaluator found it to be a wise investment. The separation of evaluation tasks from project tasks freed project staff to concentrate on making the project work, and ensured that evaluation tasks were given priority. It also facilitated knowledge transfer from evaluator to project team.

Most project plans were very detailed. This can be very useful but can also become a burden as a project unfolds. Different formats were used by projects. Successful projects tended to be more focused in their approach.

There was not always a good balance in the structure of the plans between 'getting the project done' and ensuring that the project was done well (by devoting sufficient resources to evaluation). The CCP Tool Kit was designed to overcome this, in part, by making a series of tools readily available to save projects having to develop tools themselves. This was fine in theory but, in practice, it did not prove to be as useful as anticipated. There were several reasons for this, including the timing of the Tool Kit's dissemination and the general nature of the tools.

A few projects had overly ambitious goals, or their expectations were unrealistic. Recruitment of participants and/or engagement of stakeholders was commonly much more difficult than anticipated. When their proposed methods for community engagement failed, some projects were able to adapt and innovate, with excellent results.

5.4 Sustainability

The CCP projects found that developing partnerships is a time consuming process requiring much expenditure of effort. For community-based projects, engaging stakeholders was the key issue that could 'make-or-break' the project. It is difficult to quantify such work, much less 'measure' its impact. However, it is reasonable to conclude that establishing such connections resulted in some of the most valuable work of the CCP. Successful community engagement is an important condition for project sustainability.

Some jurisdictional officers raised concerns about project sustainability, particularly the issue of raising expectations that can only be met by continued funding. We share this concern. There are several examples where CCP projects have been successful in gaining funds for further projects, which can be viewed as a positive development but also raises the prospect of exacerbating the problem. Sustainability becomes viewed in terms of gaining ongoing 'project' funds rather than incorporating the work of projects into the day-to-day business of local organisations.

The sustainability tool developed for this project proved useful in gauging how assessment of sustainability changed over the course of the evaluation and in focusing attention on this issue, particularly in the early stages of each project. However, the true test of sustainability can only come at some point in the future with a review of what has in fact been sustained – is the education program still being run, is the model of care still in place? It may be worth considering allocating a small amount of money in (say) 6-12 months time to undertake a 'stocktake' of what has been sustained.

Appendix 1 – The CCP projects indexed by theme

Table 8 below provides an index of the CCP projects.
Table 9 is a matrix identifying themes addressed by each project indicated. These themes are based on the target groups and objectives of the CCP and are not mutually exclusive, so any one project may appear under several headings (e.g., rural and remote, indigenous Australians and older Australians).

Table 8 Numbered list of Caring Communities Program projects

No	Title
ACT-1	Education Link – PC
ACT-2	Enhancing Community Understanding of Palliative Care
ACT-3	Shared Understandings Improving Palliative Care for People with Dementia
NSW-1	Developing linkages between an Indigenous population and a palliative care service
NSW-2	Helping Communities Care: Volunteer and bereavement support networks
NSW-3	Kids Grief: a handbook for group leaders
NSW-4	QTY bereavement project
NSW-5	Motor Neurone Disease Volunteer Visitor Pilot Program
NSW-6	Palliative care dementia interface: enhancing community capacity
NSW-7	Palliative care education utilising interactive satellite television technology
NSW-8	Study to predict home death
NSW-9	Supporting and educating carers in palliative care
NT-1	Greater Darwin Palliative Care Volunteer Support Project
NT-2	Groote Palliative Care Support Service
NT-3	Northern Care Frontier Services
NT-4	Visiting Specialist Program, Central Australia
QLD-1	An educational strategy to increase the palliative care capacity of primary health care providers working in rural and remote areas of Queensland
QLD-2	Bundaberg Palliative Access Link (PAL) Project
QLD-3	Community Bereavement Support Service Children, Adolescents and the Families
QLD-4	SEAM: A support, education, assessment and monitoring service for regional and rural people
QLD-5	Volunteer Palliative Care Support Network Initiative
SA-1	Establishing the care-worker role in palliative care-education, support and integration with palliative care teams
SA-2	Kangaroo Island palliative care project
SA-3	Partnering with rural communities to improve access and education in palliative care
SA-4	Shared bereavement care in the west
TAS-1	Collaborative Palliative Care in Rural Communities
TAS-2	Empowering the Southern Midlands community through information and integration
VIC-1	Best Practice Support Model for Terminal Illness in the Workplace
VIC-2	Building rural community capacity through volunteering
VIC-3	Experiential Palliative Care Program for General Practitioners
VIC-4	Improving consumer and health professional access to comprehensive, accessible, user-friendly

No	Title
	evidence-based online information
VIC-5	Living and Dying in Style
WA-1	Accessing Palliative Care in the Kimberley's Remote Aboriginal Communities
WA-2	Fitzroy Valley Palliative Care Service
WA-3	Kalgoorlie-Boulder Palliative Care Coordination Project
WA-4	Learn Now, Live Well: An Educational Program For Patients And Care-Givers Living With And Affected By Life Threatening Illness
WA-5	South West Perth Collaborative Community Palliative Care Project

Table 9 CCP projects indexed by theme

	Target Groups							Strategies							Location						
	Aboriginal people	Aged/Community Care workers	Bereaved people	Carers	Children / adolescents	Community	CALD communities	Health professionals	Older people	Palliative care patients	Volunteers	Awareness raising	Coordination of care	Direct service delivery	Education	Information	Research	Aged care facilities	Rural and remote	Schools	Workplaces
ACT-1								x							x						
ACT-2						x						x				x					
ACT-3								x							x						
NSW-1	x					x		x							x	x			x		
NSW-2			x	x		x					x	x	x	x	x				x		
NSW-3			x		x	x		x						x	x	x				x	
NSW-4			x	x		x		x		x		x			x	x					
NSW-5			x	x						x	x	x	x	x	x						
NSW-6		x		x				x	x	x			x		x	x		x			
NSW-7															x			x			
NSW-8			x	x													x				
NSW-9		x	x	x				x					x		x	x					
NT-1				x		x						x			x						
NT-2	x					x									x				x		
NT-3	x					x			x			x			x			x	x		
NT-4								x						x					x		
QLD-1								x							x			x			
QLD-2			x			x				x		x									
QLD-3			x		x	x		x				x		x	x					x	
QLD-4								x		x			x						x		
QLD-5											x			x							
SA-1		x													x			x			
SA-2				x							x				x				x		
SA-3				x							x				x				x		
SA-4	x						x	x				x		x	x	x					
TAS-1								x		x			x	x					x		
TAS-2						x		x				x			x						

	Target Groups							Strategies							Location							
	Aboriginal people	Aged/Community Care workers	Bereaved people	Carers	Children / adolescents	Community	CALD communities	Health professionals	Older people	Palliative care patients	Volunteers	Awareness raising	Coordination of care	Direct service delivery	Education	Information	Research	Aged care facilities	Rural and remote	Schools	Workplaces
VIC-1			x	x		x				x		x				x	x				x
VIC-2						x					x	x		x					x		
VIC-3								x							x				x		
VIC-4				x		x		x								x					
VIC-5		x						x						x	x				x		
WA-1	x									x			x						x		
WA-2	x						x	x				x	x						x		
WA-3		x		x				x					x	x					x		
WA-4				x						x											
WA-5		x		x				x		x			x								